TESTING A MODEL OF COMMUNICATION, UNCERTAINTY, AND EMOTIONAL WELL-BEING IN OLDER BREAST CANCER SURVIVORS

by
Margaret F. Clayton

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirement for the degree of Doctor of Philosophy in the School of Nursing.

Chapel Hill
2003

ABSTRACT

MARGARET F. CLAYTON

Testing a Model of Communication, Uncertainty, and Emotional Well-Being in Older Breast Cancer Survivors

(Under the direction of Dr. Merle H. Mishel RN, PhD, FAAN)

The uncertainty and disruption caused by ongoing physical symptoms contributes to emotional distress and thoughts of recurrence for older breast cancer survivors. Uncertainty may be due to a lack of information about whether symptoms indicate recurrence, are related to comorbid conditions, or are part of the normal aging process.

The purpose of this research was to assess the influence of physical symptoms, age, ethnicity, and patient- provider communication, on the uncertainty and emotional well-being of older breast cancer survivors. Guided by Uncertainty in Illness Theory, a conceptual model was developed and tested using structural equation modeling techniques. Data from 203 recurrence free Caucasian and African American women age 50-91, and 5-9 years post original treatment were used to test the model.

Women reported an average of 5 symptoms, with only 12% of women reporting no physical symptoms. In addition, results suggest that high levels of symptom bother may place survivors at risk for adverse emotional well-being.

Women reported high levels of symptom bother from weight gain, fatigue, pain, trouble thinking, and arm problems. These were not the most prevalent symptoms.

Age was the strongest predictor of emotional well-being. Increasing age predicted less symptom bother, less uncertainty, less mood disturbance, and fewer troublesome thoughts of recurrence. Ethnicity was not significant in predicting either uncertainty or emotional well-being.

Larger amounts of patient-provider communication predicted increased troublesome thoughts of recurrence. Possibly women received a more lengthy discussion of their symptoms than desired or expected. Conversely, it may be that a larger number of troublesome thoughts of recurrence triggered more talk between patient and provider.

Communication findings showed that over 40% of women were unable to achieve their desired decision-making role. The high level of discrepancy between desired versus attained decision-making roles raises the issue of whether providers are meeting the ethical responsibility of respecting the autonomy of their patients or still adhering to a paternalistic model of care-giving.

Future research is needed to investigate the long-term consequences of persistent uncertainty. Additionally, future research will clarify the mechanism by which patient-provider communication influences troublesome thoughts of recurrence for older breast cancer survivors.

In memory of Jean D. Francis

My mother

ACKNOWLEDGEMENTS

What does one say as one completes a dream? To say thank you seems inadequate, yet it is also the simplest and most complete statement of gratitude. My committee has guided, shaped, and taught me. My friends have walked with me, celebrating and commiserating. My family has loved and supported me.

My mentor Merle Mishel has provided me with an outstanding role model for research. She also gave me her friendship thru dinners, movies, and gardening. Barbara Germino gave me the encouragement and guidance so necessary to this journey. Her friendship is a highly valued treasure. She had faith in me, and in my ability to “survive” the rigors of doctoral education. Michael Belyea is the only person who ever managed to increase my understanding of statistics. His open door policy, kind demeanor, and patience made a difficult subject not only less difficult, but fascinating. Diane Kjervik has been a true friend and steady presence, always gracious, always offering insightful comments. Finally, Dale Brashers has expanded my knowledge of communication and helped me to bridge the gap between communication and nursing. His insight, coupled with warmth, kindness, and support have made him a colleague I shall always value.

I could not have completed this journey without my friends. Trisha, Stewart, Vivian, Liz, Val, Kopriva: The good times have not ended. Thank you from the bottom of my heart for the gift of your friendship.

Sometimes people shape your life in ways you never dreamed of. Joanne Singleton, my first mentor and lifelong friend is such a person. Without you, Joanne, I would not be here today. And to Danny Aronzon: You showed me what was possible and stood by me for 20+ years. Thank you my friend. Finally, to Mona Bingham: A friend for life. While others gave me the vision, you gave me the courage. With you as my teacher, I learned to embrace the future, rather than fear the unknown. A priceless gift freely offered and gratefully received.

Finally, my family has been my island of calm in a stormy sea. Sarah and Bill, dreams really do come true. You are my life. I rejoice in your future, I am proud of you both. I love you. Laurie you have helped me beyond measure. I am so lucky to have you as a sister. John, my wonderful brother, you showed me how to persevere for what is important. And to my father: a role model beyond compare. Your confidence and support was always quietly available whenever I needed it. Your ideas showed me the importance of dreaming. Your accomplishments showed me goals were attainable. Your love showed me what was important in life. You taught me how to fly.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Communication, Uncertainty, and Emotional Well-Being in Breast Cancer Survivors

CHAPTER ONE: PURPOSE AND AIMS

Introduction

In the 1940's 72% of women diagnosed with localized breast cancer survived 5 years or longer (American Cancer Society, 2002). In the 1970's the survival rate of women with breast cancer improved to 75% and in the 1980's to 78% (American Cancer Society, 2002). Today, this steady decline in mortality due to breast cancer suggests that 97% of Caucasian and 87.5% of African-American women diagnosed with localized breast cancer are expected to survive 5 years or longer (American Cancer Society, 2001b; American Cancer Society , 2002; Thomas, Jemal, & Thun, 2001). Along with improved survival, the incidence of breast cancer continues to rise, with estimates that 203,500 women were diagnosed with breast cancer in 2002 (American Cancer Society , 2002). Indeed, among African American women breast cancer continues to be the most commonly diagnosed cancer (Hill-Harmon, Greenlee, & Thun, 2000) yet African American breast cancer survivors have been consistently under-represented in breast cancer research (Meyerowitz, Richardson, Hudson, & Leedham, 1998).

Breast cancer is considered a disease of older women, yet the needs of older breast cancer survivors remain largely unknown (Jacobs & Hobbie, 2002; Ludwick, Rushing, & Biordi, 1994). In 2001 it is estimated that 77% of newly diagnosed breast cancer occurred in women older than 50 years of age (American Cancer Society, 2001a). As the percentage of survivorship increases, so does the percentage of older women who are managing both the long-term side effects caused by their original treatment for breast cancer and the normal physiological changes of the aging process (Leedham & Ganz, 1999). The complex interaction of physical symptoms due to breast cancer treatment and aging generate uncertainty about how to identify physical changes due to breast cancer, and uncertainty about the potential for recurrence.

Background and Significance

Many breast cancer survivors experience physical symptoms that impact daily life due to their original treatment for breast cancer (Ferrans, 1994). Some women report being more afraid of how incapacitated they may become due to these ongoing symptoms rather than about how others view their altered bodies (Cohen, Kahn, & Steeves, 1998). It has been found that as many as 84% of women who are 5 to 8 years post treatment complain of at least one ongoing physical symptom such as fatigue or pain (Mishel et al., 2002). Those who have undergone chemotherapy are especially affected by physical symptoms (Bower et al., 2000; Mast, 1998a; Polinsky, 1994). Additionally, elderly African American breast cancer survivors have been found to experience higher levels of symptom distress when compared to African Americans with other forms of cancer (O'Hare, Malone, Lusk, & McCorkle, 1993).

Common physical complaints experienced by breast cancer survivors include arm problems, fatigue, and pain. Additionally, the concerns of African-American women are similar to Caucasian women, but they are not identical. Wilmoth (2001) found that African-American women are especially concerned with symptoms related to body image such as keloid formation from scar tissue, and the total loss of body hair. Other cultural differences may revolve around the interpretation and meaning of these physical symptoms as well as cultural definitions of ideal body image (Baturka, Hornsby, & Schorling, 2000; Wilmoth & Sanders, 2001).

Moreover, older breast cancer survivors have reported enduring treatment related side effects that they have never discussed with their providers (Crooks, 2001). In addition to their physical symptoms many older breast cancer survivors experience ongoing emotional symptoms such as depression, low self-esteem, negative body image, anger, and anxiety (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Loescher, Clark, Atwood, Leigh, & Lamb, 1990; Polinsky, 1994). However, it is difficult to distinguish the specific emotional concerns of older women because although the mean age of participants in these studies was above 50 years, all included a percentage of younger women.

Many women are unable to interpret whether their physical symptoms are indicative of recurrence. The distress and disruption caused by these symptoms contributes to uncertainty and emotional distress for breast cancer survivors (Mast, 1998b). Particular sources of uncertainty for breast cancer survivors include the inability to judge the meaning and significance of new or ongoing symptoms, the presence of new physical symptoms, and a lack of information to assist them in distinguishing whether their symptoms indicate recurrence (Dorval et al., 1998; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997a; Hilton, 1988). In particular, older women, less educated women, and women with other illnesses may be unable to decide whether the cause of their physical symptoms is the aging process, their other illnesses, or a recurrence of their breast cancer (Crooks, 2001; Mast, 1998a).

Recurrence has been described by breast cancer survivors as a major fear (Johnson Vickberg, 2001). It is known to persist among the vast majority of women for at least 8 years after their original treatment for breast cancer (Polinsky, 1994). It is likely that this fear persists even longer (Gray et al., 1998). One of the most common triggers of the fear of recurrence is the occurrence of new physical symptoms, experienced by as many as 84% of women (Mishel et al., 2002). Other common triggers include having a known survivor that experiences worsening disease, medical appointments, and information on breast cancer seen in the media (Mishel et al., 2002). This fear of recurrence creates emotional distress, anxiety and uncertainty for the breast cancer survivor (Ferrell et al., 1996; Mishel, 1999; Pelusi, 1997).

Mishel (1988) has defined uncertainty as an inability to create meaning from unfamiliar stimuli. For breast cancer survivors, sources of uncertainty include an inability to judge whether new or ongoing symptoms indicate a recurrence of their breast cancer. The presence of unfamiliar physical symptoms may also cause uncertainty. Further, lack of information about the origin and management of their symptoms may contribute to uncertainty and impact their psychosocial quality of life (Dorval et al., 1998; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997b; Mast, 1998b). There is evidence that fear of recurrence and uncertainty about the future are major concerns of breast cancer survivors (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Hilton, 1988).

When women are unable to interpret the meaning of their symptoms, the resulting uncertainty and anxiety about recurrence contributes to emotional distress (Bleiker et al., 2000; Halstead & Fernsler, 1994; Mast, 1998b; Polinsky, 1994). This uncertainty and distress may cause women to seek information and advice from their healthcare provider (Gray et al., 1998; Rees A, 2000). However, older women report that they are treated differently by their providers, especially about how and what kind of information is shared with them (Crooks, 2001). Older women have reported that information about treatment choices for their breast cancer often were presented without interpretation, making informed decision making difficult (Crooks, 2001). Additionally, women report that their questions were not answered sufficiently (Crooks, 2001). Moreover, some literature shows that providers make assumptions about the needs and wishes of older women, such as older women accept a diagnosis of cancer more easily than younger women, and that older women do not care as much about the loss of their breast, or that older women prefer not to be involved in decision-making (Crooks, 2001).

Similarly, breast cancer survivors report that providers do not understand or pay attention to their symptoms (Loescher et al., 1990) or report that they are unhappy with the communication skills of their oncologist (Wilmoth, 2001). Some women complain that providers overlook their emotional concerns, focusing only on their physical symptoms (Watson, Haviland, Greer, Davidson, & Bliss, 1999). Still other sources of communication difficulties may occur when patients and providers prioritize concerns differently, (Goldberg, Guadagnoli, Silliman, & Glicksman, 1990), or when women are unable to assume the role they desire (passive, active, or collaborative) in the medical exchange (Degner & Sloan, 1992; Degner et al., 1997b). The result of this communication deficit among patients, and the incorrect assumptions of providers, is a reduced awareness by health care providers of the emotional and physical concerns experienced by older breast cancer survivors.

Recognizing the importance of patient-provider communication, many studies have focused on improving the communication skills of patients and / or providers

(Cegala, 1997; Cegala, Marinelli, & Post, 2000; Levinson & Roter, 1993; Thompson, 1998). However, studies have not considered the complexity of the communication process and have ignored variables that may influence patient-provider communication. Such variables include the role patients wish to play in the medical interview, their perceived involvement in the medical interaction, and the discrepancy between desired and achieved role in the medical interaction.

The role one wishes to play in the medical exchange has been shown to be an important aspect of patient-provider communication varying with the disease trajectory (Degner & Sloan, 1992), information management strategy (Brashers et al., 2000b), and individual characteristics (Degner & Sloan, 1992; Degner, 1992; Ende, Kazis, Ash, & Moskowitz, 1989). Moreover, although specific individual characteristics such as age (Beisecker, 1988) or ethnicity (McKinley, Garrett, Evans, & Danis, 1996) have been found to be influential in the patient-provider relationship, investigators have ignored the interaction of these characteristics with the complex process of patient-provider communication on disease severity.

The literature on symptom management, uncertainty, and emotional well-being point to the important role of the healthcare provider in enhancing overall quality of life and emotional well-being for patients with a multitude of diagnoses. This study will focus on the role of healthcare providers in reducing symptom burden and levels of uncertainty and the emotional well-being of older African-American and Caucasian breast cancer survivors. Additionally the impact of age and ethnicity on the interaction between structure providers (education and credible authorities) and the stimuli frame (symptom pattern) were assessed. It is hoped that by increasing our understanding of factors that influence uncertainty and the emotional well-being of these women, areas for potential intervention were identified that will assist women to manage their experience of being a breast cancer survivor in a positive fashion.

Although the issues and concerns of breast cancer survivors have been identified in the literature, including the existence of late treatment side effects, fear of recurrence, and evidence that communication with healthcare providers is important to these women, methodological problems make comparison across studies difficult. Much of the existing literature has included samples of women with vastly different characteristics. Other research studies combine breast cancer patients with multiple types of cancer diagnoses (Turk-Charles, Meyerowitz, & Gatz, 1997; Wyatt & Friedman, 1996). Despite the fact that breast cancer survivors may have some issues in common with other cancer survivors, and that women of different ages and life stages may have some concerns that are similar, it is not reasonable to assume that all women or all cancer survivors are alike. There is evidence that the individual experiences of breast cancer survivors are influenced by disease severity, age, and time since diagnosis (Vinokur, Threatt, Caplan, & Zimmerman, 1989). Further, it has been shown that the experiences and concerns of patients vary with the type of cancer diagnosis (Beaver, Bogg, & Luker, 1999). An additional sampling problem is the lack of inclusion of African-American women (Meyerowitz et al., 1998), resulting in the needs of these women remaining largely unknown (Leedham & Ganz, 1999). Studies that include women with vastly different individual characteristics make it difficult to identify unique needs of specific groups of breast cancer survivors. The result of these methodological problems is that the needs of older breast cancer survivors, especially African American survivors, remain unknown and therefore unaddressed by health care providers.

A second problem with much of the current work among breast cancer survivors is that the majority of this research is atheoretical. When variables are selected without theoretical relevance, there is the potential for important variables to be overlooked. An example is the exclusion of the patient-provider relationship in research addressing the impact of long-term side effects on outcomes such as quality of life for breast cancer survivors. Uncertainty in Illness Theory predicts that a credible authority (terms defined in Appendix A) such as a healthcare provider, provides structure to the illness experience and affects patients' levels of uncertainty, which in turn may affect adaptation to the illness experience (Mishel & Braden, 1988; Mishel, 1988). Among breast cancer survivors there is empirical evidence supporting the importance of the patient-provider relationship to these women (Wilson, Andersen, & Meischke, 2000). Moreover, there is evidence that this relationship may impact other outcome variables such as quality of life (Ganz et al., 1996) and psychological adaptation (Wilson et al., 2000). Thus, Uncertainty in Illness Theory demonstrates the importance of, and provides a rationale for including the process of patient-provider communication in research investigating the needs, concerns, and adaptation of older breast cancer survivors.

Another problem with the atheoretical selection of variables is that there is the potential for selection of outcome variables that are not of primary concern to the sample under investigation. For example, literature investigating the impact of variables such as sexuality and body image is frequently conducted among populations of older women (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999) or among mixed samples of older as well as younger women (Wilmoth, 2001). Yet older breast cancer survivors have been shown to be more concerned with maintaining physical functioning and independence, rather than issues of body image or difficulty with intimacy possibly because as women age they are less likely to be involved in new relationships and are more likely to be living alone or in stable relationships (Cameron & Horsburgh, 1998b; Vinokur et al., 1989). Thus, the result of an atheoretical selection of variables is an analysis of outcomes that may not fully address the issues important to the population being studied, such as the specific concerns of older women, minority women, and women at different points along their illness trajectory.

Lastly, much of the breast cancer survivor literature has examined variables as independent predictors of outcomes, without regard for interactions that may help in understanding the complexity of why, and when outcomes occur. For example, fear of recurrence and the presence of physical symptoms have been found to be predictors of uncertainty and emotional status (Mast, 1998b), yet have not been viewed as part of a complex process that may include the interaction of these variables along with the patient- provider relationship as significant predictors of uncertainty and emotional well-being.

Consequently, due to methodological problems with sample selection, the atheoretical nature of existing research, and the analysis of variables as independent predictors rather than as part of a process, it is difficult to make comparisons among studies and build knowledge about the complex process of breast cancer survivorship. Breast cancer survivors represent a diverse population of women. Research that uses theory to select variables and identify issues important to a sample of older women will contribute to knowledge about the process of survivorship among a rapidly growing population of older breast cancer survivors, and ultimately facilitate the targeting of interventions addressing the unique needs of this population.

The Current Study

The current study will test predictors of uncertainty and emotional well-being among older breast cancer survivors using a causal model (Figure 1.1) developed from Uncertainty in Illness Theory (Mishel, 1988). Specifically, this model will test the influence of age, structure providers encompassing education and the patient-provider relationship, and the stimuli frame encompassing physical symptoms, for their impact on uncertainty, and ultimately on the emotional well-being, of older breast cancer survivors (Figure 1.1). Emotional well-being were defined as the amount of troublesome thoughts of recurrence, as well as the subject's mood state. Based on indications that there may be cultural variations in the patient-provider relationship as well as in goals and priorities, this study will include both Caucasian American and African American breast cancer survivors.

Data for this study were obtained from the control groups of three separate studies. The largest number of women were obtained from an ongoing intervention study: Managing Uncertainty in Older Breast Cancer Survivors study (NIH/NCI 5R01 CA 78955-03 P. I. Merle Mishel). This ongoing study is an intervention study designed to help older breast cancer survivors manage their physical long-term treatment side effects and the continued fear of recurrence by using a series of self-administered audio-taped cognitive coping skills, as well as a manual of management resources. Data for both intervention and control subjects are collected at baseline, 12 months and 20 months after enrollment. Subjects are women over age 50 who are 5-9 years from their original diagnosis and treatment and have not experienced recurrence. These subjects were identified with the assistance of tumor registries across the state. Subjects were obtained from the control group of this ongoing study, and measured at the last data collection point. Subjects will also be obtained from the control groups of two other previous studies as part of a planned long-term follow-up of these two studies of breast cancer patients undergoing treatment, as they join the ongoing study by becoming age fifty or older and five or more years post their original treatment. Promoting self-help: Underserved women with breast cancer (R01 CA 64706-02 PI: C. Braden and Managing uncertainty: Self help in breast cancer (R01 CA 57764-04 PI: M. Mishel). The total number of control subjects available for this secondary analysis is 203.

Instruments used to measure selected variables were the same as in the larger study and are described in chapter three. However, the inclusion of two additional instruments to measure the patient's perception of involvement in the medical exchange and the desired vs attained role will allow greater exploration of how the patient-provider relationship influences uncertainty in this population.

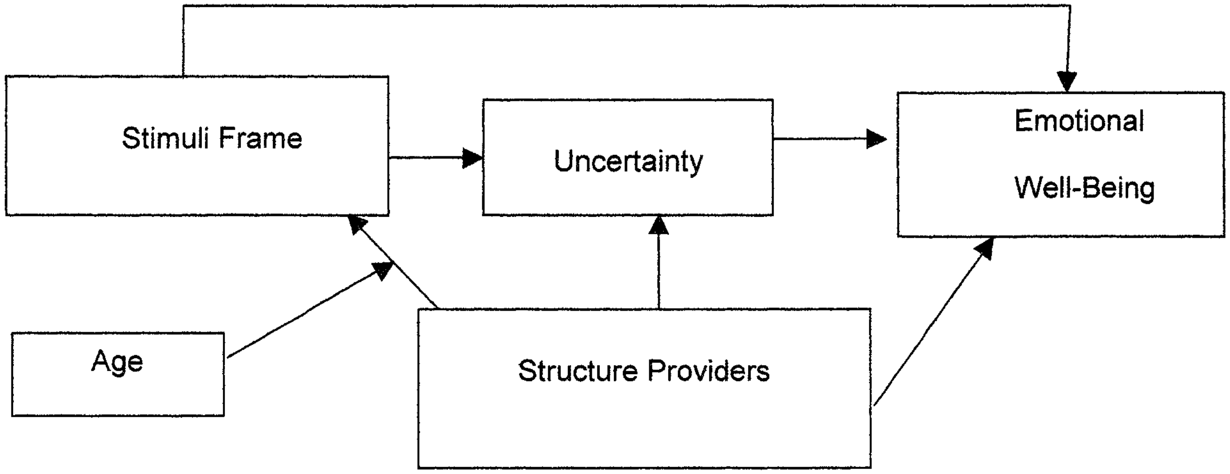
Summary

It has been established that the existing population of older breast cancer survivors is increasing, and that these women experience many unmet needs and communication issues with their healthcare provider. These concerns may contribute to uncertainty, which in turn may affect the emotional well-being of breast cancer survivors. The existing research on older survivors has suffered from methodological problems, as well as a lack of inclusion of African American women. Further, the complexity of the interaction of age, education, and physical symptoms, along with the evolving recognition of the importance of the patient-provider relationship, on uncertainty has yet to be investigated. This study will investigate this complex relationship by testing a conceptual model derived from Mishel's Uncertainty in Illness theory. As the complex processes that affect uncertainty and emotional well-being become more fully understood, it is hoped that interventions were developed to assist in meeting the needs of the older breast cancer survivor in a culturally competent manner.

Research Aim

The aim of this study is to develop and test a conceptual model to discover factors that individually or in interaction, predict levels of uncertainty and emotional well-being in a population of older African-American and Caucasian breast cancer survivors (Figure 1.1).

Figure 1.1 Conceptual Model of Uncertainty and Emotional Well-Being in Older Breast Cancer Survivors.



Research Questions

A. Does the stimuli frame influence the level of uncertainty of older breast cancer survivors?

1. Is the number of physical symptoms associated with the level of uncertainty in older breast cancer survivors?
2. Is the bother of existing physical symptoms associated with the level of uncertainty in older breast cancer survivors?

B. Does the stimuli frame influence emotional well-being in older breast cancer survivors?

1. Is the number of physical symptoms associated with the mood state of older breast cancer survivors?
2. Is the number of physical symptoms associated with troublesome thoughts of recurrence in older breast cancer survivors?
3. Is the bother of existing physical symptoms associated with the mood state of older breast cancer survivors?
4. Is the bother of existing physical symptoms associated with the amount of troublesome thoughts of recurrence for older breast cancer survivors?

C. Do structure providers influence the stimuli frame in older breast cancer survivors?

1. Is education associated with the number of reported symptoms in older breast cancer survivors?
2. Is education associated with the bother of existing physical symptoms in older breast cancer survivors?
3. Is the amount of patient-provider communication associated with the number of reported symptoms in older breast cancer survivors?

4. Is the amount of patient-provider communication associated with the bother of existing physical symptoms in older breast cancer survivors?
5. Is the perception of involvement in decision-making associated with the number of reported symptoms in older breast cancer survivors?
6. Is the perception of involvement in decision-making associated with the bother of existing physical symptoms in older breast cancer survivors?
7. Is a woman's desired role preference associated with the number of reported symptoms in older breast cancer survivors?
8. Is a woman's desired role preference associated with the bother of existing physical symptoms in older breast cancer survivors?
9. Is the discrepancy between the desired and attained decision-making role preference associated with uncertainty in older breast cancer survivors?
10. Is the discrepancy between the desired and attained decision-making role preference associated with the number of reported symptoms in older breast cancer survivors?
11. Is the discrepancy between the desired and attained decision-making role preference associated with the bother of existing physical symptoms in older breast cancer survivors?

D. What factors moderate the relationship between structure providers and the stimuli frame in older breast cancer survivors?

1. Does age moderate the relationship between education and the number of reported symptoms in older breast cancer survivors?
2. Does age moderate the relationship between education and the bother of existing physical symptoms in older breast cancer survivors?

3. Does age moderate the relationship between the amount of patient-provider communication and the number of reported symptoms in older breast cancer survivors?
4. Does age moderate the relationship between the amount of patient-provider communication and the bother of existing physical symptoms in older breast cancer survivors?
5. Does age moderate the relationship between the perception of involvement in decision-making and the number of reported symptoms in older breast cancer survivors?
6. Does age moderate the relationship between the perception of involvement in decision-making and the bother of existing physical symptoms in older breast cancer survivors?
7. Does age moderate the relationship between a woman's desired role preference and the number of reported symptoms in older breast cancer survivors?
8. Does age moderate the relationship between a woman's desired role preference and the bother of existing physical symptoms in older breast cancer survivors?
9. Does age moderate the relationship between the discrepancy of desired and attained decision-making role preference, and the number of reported symptoms in older breast cancer survivors?
10. Does age moderate the relationship between the discrepancy of desired and attained decision-making role preference, and the bother of existing physical symptoms in older breast cancer survivors?

11. Does ethnicity moderate the relationship between education and the number of reported symptoms in older breast cancer survivors?
12. Does ethnicity moderate the relationship between education and the bother of existing physical symptoms in older breast cancer survivors?
13. Does ethnicity moderate the relationship between the amount of patient-provider communication and the number of reported symptoms in older breast cancer survivors?
14. Does ethnicity moderate the relationship between the amount of patient-provider communication and the bother of existing physical symptoms in older breast cancer survivors?
15. Does ethnicity moderate the relationship between the perception of involvement in decision-making and the number of reported symptoms in older breast cancer survivors?
16. Does ethnicity moderate the relationship between the perception of involvement in decision-making and the bother of existing physical symptoms in older breast cancer survivors?
17. Does ethnicity moderate the relationship between a woman's desired role preference and the number of reported symptoms in older breast cancer survivors?
18. Does ethnicity moderate the relationship between a woman's desired role preference and the bother of existing physical symptoms in older breast cancer survivors?
19. Does ethnicity moderate the relationship between the discrepancy of desired and attained decision-making role preference and the number of reported symptoms in older breast cancer survivors?

20. Does ethnicity moderate the relationship between the discrepancy of desired and attained decision-making role preference and the bother of existing physical symptoms in older breast cancer survivors?

E. Do structure providers influence uncertainty in older breast cancer survivors?

1. Is education associated with uncertainty in older breast cancer survivors?
2. Is the amount of patient-provider communication associated with uncertainty in older breast cancer survivors?
3. Is the perception of involvement in decision-making associated with uncertainty in older breast cancer survivors?
4. Is a woman's desired role preference associated with uncertainty in older breast cancer survivors?
5. Is the discrepancy between the desired and attained decision-making role preference associated with uncertainty in older breast cancer survivors?

F. Does uncertainty influence the emotional well-being of older breast cancer survivors?

1. Is the level of uncertainty of older breast cancer survivors associated with their mood state?
2. Is the level of uncertainty of older breast cancer survivors associated with troublesome thoughts of recurrence?

G. Do structure providers influence the emotional well-being of older breast cancer survivors?

1. Is education associated with mood state in older breast cancer survivors?
2. Is the amount of patient-provider communication associated with mood state in older breast cancer survivors?

3. Is the perception of involvement in decision-making associated with mood state in older breast cancer survivors?
4. Is a woman's desired role preference associated with mood state in older breast cancer survivors?
5. Is the discrepancy between the desired and attained decision-making role preference associated with mood state in older breast cancer survivors?
6. Is education associated with troublesome thoughts of recurrence in older breast cancer survivors?
7. Is the amount of patient-provider communication associated with troublesome thoughts of recurrence in older breast cancer survivors?
8. Is the perception of involvement in decision-making associated with troublesome thoughts of recurrence in older breast cancer survivors?
9. Is a woman's desired role preference associated with troublesome thoughts of recurrence in older breast cancer survivors?
10. Is the discrepancy between the desired and attained decision-making role preference associated with troublesome thoughts of recurrence in older breast cancer survivors?

H. Does uncertainty mediate the relationship between structure providers and emotional well-being in older breast cancer survivors?

1. Does uncertainty mediate the relationship between education and mood state in older breast cancer survivors?
2. Does uncertainty mediate the relationship between education and troublesome thoughts of recurrence in older breast cancer survivors?
3. Does uncertainty mediate the relationship between the amount of patient-provider communication and mood state in older breast cancer survivors?

4. Does uncertainty mediate the relationship between the amount of patient-provider communication and troublesome thoughts of recurrence in older breast cancer survivors?
5. Does uncertainty mediate the relationship between the perception of involvement in decision-making and mood state in older breast cancer survivors?
6. Does uncertainty mediate the relationship between the perception of involvement in decision-making and troublesome thoughts of recurrence in older breast cancer survivors?
7. Does uncertainty mediate the relationship between a woman's desired role preference and mood state in older breast cancer survivors?
8. Does uncertainty mediate the relationship between a woman's desired role preference and troublesome thoughts of recurrence in older breast cancer survivors?
9. Does uncertainty mediate the relationship between the discrepancy of desired and attained decision-making role preference, and mood state in older breast cancer survivors?
10. Does uncertainty mediate the relationship between the discrepancy of desired and attained decision-making role preference, and troublesome thoughts of recurrence in older breast cancer survivors?

CHAPTER TWO: REVIEW OF THE LITERATURE

Introduction

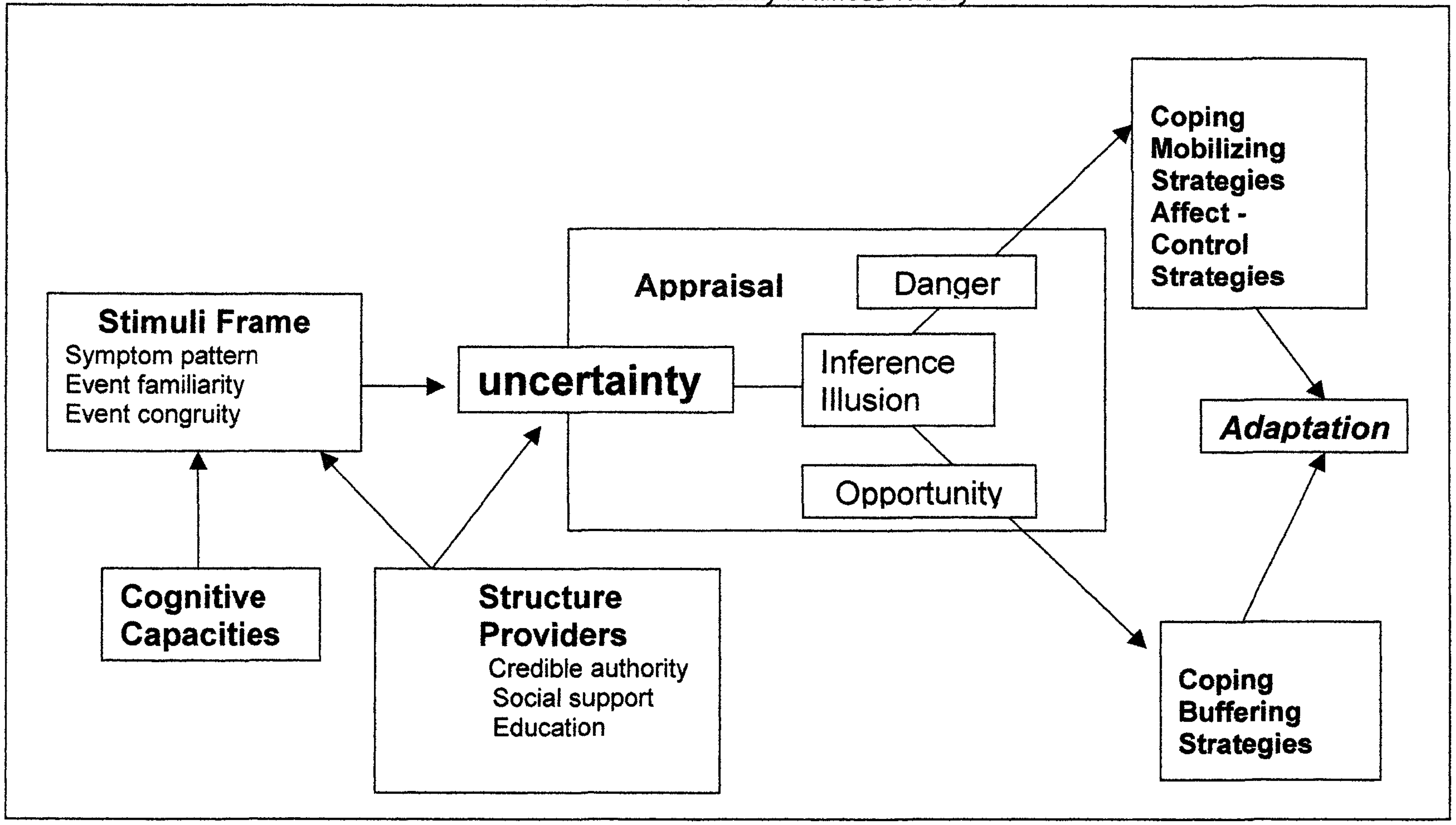
In this chapter, literature on uncertainty were reviewed and discussed. Additionally, literature on age, education, ethnicity, symptom distress, and patient-provider communication in relation to older breast cancer survivors were reviewed and placed within the theoretical context of uncertainty in illness. The review is organized to follow and explicate the links previously presented in the proposed conceptual model (Chapter 1, Figure 1.1). The original theory is presented in Figure 2.1.

Overview of Uncertainty Theory

Patient uncertainty was originally conceptualized to reflect the anxiety associated with the ambiguity of illness, and the inability to cope effectively with this ambiguity (Lazarus, 1974; Lazarus & Folkman, 1984). Subsequent work by Mishel (1988) broadened this original conceptualization to include antecedents of uncertainty linking the concept with illness. Originally, uncertainty was conceptualized as linear, resolving with time and information, and primarily associated with the acute treatment and diagnosis phase of illness (Mishel, 1988). Uncertainty is associated with a specific illness event, and is a neutral state that is subsequently appraised as danger or

Figure 2.1 Model of Uncertainty in Illness: Mishel, M.H. (1988). Uncertainty in illness. Image: Journal of Nursing Scholarship 20(4),225-232.

Overview of Uncertainty in Illness Theory



opportunity (Figure 2) (Mishel, 1997). Based upon an individual's appraisal of danger or opportunity, adaptation results. This is in contrast to other conceptualizations of uncertainty that define uncertainty as an emotional state or feeling, rather than a neutral cognitive state (Hilton, 1994; McCormick, 2002).

Uncertainty is theorized to encompass four dimensions: ambiguity, complexity, lack of information, and unpredictability, and is defined as an inability to created meaning from illness related events (Mishel, 1981; Mishel, 1988; Mishel & Braden, 1988). Uncertainty in illness theory focuses on how patients determine the meaning of an illness experience, and is operationalized to occur in situations where insufficient cues create an inability to predict future outcomes. The resulting uncertainty has been shown to be associated with emotional distress and overall reduced quality of life (Mast, 1995). This view of uncertainty is representative of a view of uncertainty as being an undesirable state that the patient wishes to avoid.

A primary antecedent of uncertainty is the stimuli frame, reflecting a patient's symptom pattern, the familiarity of events within the healthcare system, and the congruence between actual and experienced illness events (Mishel, 1988). The lack of a stimuli frame is proposed to have an inverse relationship with uncertainty (Mishel & Braden, 1988; Mishel, 1988). Uncertainty is reduced when patterns among symptoms and events can be detected, and when illness events can be predicted. The stimuli frame is also influenced by a patient's cognitive capacity. Thus when cognition is impaired for whatever reason, the ability to interpret and predict symptoms and events is even more difficult.

The second major antecedent of uncertainty is structure providers, or the resources available to assist the patient to interpret symptoms and illness related events (Mishel & Braden, 1988; Mishel, 1988). A major mechanism for reducing uncertainty directly via a structure provider is the acquisition of information (Mishel & Braden, 1988). The provision of information by a credible authority such as a healthcare provider is thought to be a major factor in reducing uncertainty by enhancing the familiarity and predictability of events and symptoms and providing meaning to illness events (Mishel, 1997). Indirectly, structure providers such as social support systems, healthcare providers, and the patient's educational level, influence uncertainty through the stimuli frame by facilitating an understanding of symptoms and events (Mishel & Braden, 1988; Mishel, 1988).

Mishel has expanded the concept of uncertainty to include patients living with chronic illness (Mishel, 1990). In the reconceptualization of Uncertainty in Illness Theory, it was suggested that patients living with chronic diseases and those who live with a continual fear of recurrence, such as breast cancer survivors, may eventually reprioritize their goals and values thus enabling them to live with continual uncertainty (Mishel, 1990). This reconceptualization does not view uncertainty as an aversive state, rather, in this view, uncertainty may be preferable to a known certainty in diagnoses such as cancer or HIV/AIDS. In the reconceptualized theory, patients may eventually view uncertainty as a positive rather than a negative state (Mishel, 1990; Mishel & Clayton, in press). Additionally, research suggests that some persons may wish to preserve uncertainty as a way of maintaining hope, supporting Mishel's view that uncertainty can be thought of as a positive experience (Brashers et al., 2000b).

Uncertainty in Cancer Patients

Research testing and/or supporting Uncertainty in Illness Theory has been conducted with many different populations including cancer patients. Early work by Molleman et al. (1984) found that uncertainty in cancer patients is related to the unpredictable course of illness as well as to questions regarding the efficacy of treatment. This study of 418 cancer patients found that information gathering was a predominant method of reducing uncertainty. Molleman and colleagues (1984) suggested that uncertainty arises from unpredictable situations, as opposed to anxiety, which arises from menacing situations. Molleman et al (1984) found that the role of the provider as expert was the most effective way of reducing uncertainty in cancer patients, however, these researchers also found that not all patients preferred to discuss their problems with their healthcare provider, suggesting that patients manage information differently during interactions with their healthcare provider. Research by Mishel and Braden (1988) supports the importance of the patient-provider relationship. They found that the patient-provider relationship accounted for 35% of the variance in uncertainty among 61 women with gynecological cancer.

More recent research on uncertainty in cancer patients continues to support the influence of information gathering in reducing uncertainty. Galloway and Graydon (1996) found that patients with colon cancer experienced low symptom distress in the hospital environment, but high uncertainty about how to manage symptoms at home. Those with more uncertainty were found to desire more discharge information. In a study of a sample of cancer patients with a mixture cancer diagnoses, uncertainty was found to be a motivator of the intent to seek information from providers, although 22% of patients in this sample did not actually follow through with information seeking behaviors (Borgers et al., 1993).

The previous research assumes that the primary goal of cancer patients is to reduce uncertainty. Most recently, research has focused on the management, rather than the reduction, of uncertainty. To test the hypothesis that uncertainty management is beneficial to patients, Mishel and colleagues delivered a psychoeducational intervention to 239 men with prostate cancer, showing that a telephone - based intervention to manage uncertainty effectively enhanced cognitive reframing and problem solving skills, as well as reduced the severity of incontinence (Mishel et al., 2002b). Other related research has examined the management of uncertainty from the perspective of communication, showing that varying information management styles can be used as a way of maintaining, reducing, or increasing patient uncertainty and thus preserve hope in a sample of HIV/AIDS patients (Brashers et al., 2000b).

Uncertainty in Breast Cancer Patients

Early qualitative work discovered that uncertainty was a problem for newly diagnosed breast cancer patients (Hilton, 1988). Subsequent work revealed that women who had high levels of uncertainty along with high fears of recurrence used social support and problem solving techniques as coping methods to manage their uncertainty (Hilton, 1989). Later research by Wong and Bramwell (1992) found no difference in levels of uncertainty prior to and post discharge following mastectomy. These researchers concluded that uncertainty persists beyond the treatment phase for women who have undergone mastectomies, and further, that women fear recurrence during the treatment and immediate post treatment phase of illness, thus contributing to increased levels of uncertainty (1992). Research by Deane and Degner (1998) found that uncertainty for women who had undergone breast biopsy with benign results was highest during the time they were waiting for diagnosis. This work supports other findings among breast cancer patients showing that levels of uncertainty are higher while awaiting a diagnosis (Hilton, 1993; Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995).

Following the present trend of focusing on uncertainty management, rather than reduction, Braden and colleagues were able to show that an uncertainty management intervention improved psychological adjustment as well as self care and self helping skills, in a sample of women undergoing treatment for breast cancer (Braden, Mishel, & Longman, 1998). Another nurse-delivered intervention proved effective in improving quality of life through improved mood states and lower uncertainty among 210 newly diagnosed women that were followed for 2 years (Ritz et al., 2000). Still other uncertainty management research with breast cancer patients has investigated the role of social support in reducing, maintaining or increasing uncertainty (Ford, Babrow, & Stohl, 1996). The findings from this research support the influence of communication, in this case among support group members, as an important uncertainty management tool among breast cancer patients (Ford et al., 1996).

One of the problems with the literature discussing uncertainty and breast cancer patients is the inclusion of women with breast cancer as well as other cancer diagnoses in samples being investigated (Turk-Charles et al., 1997). Additionally, studies of women with breast cancer include women with age ranges of as much as 55 years (Ritz et al., 2000), yet the treatment and related side effects may differ by age, and women of different ages may have different sources of uncertainty. This makes is difficult to discern factors that contribute to uncertainty among age and disease specific populations of breast cancer patients.

Uncertainty in Breast Cancer Survivors

The literature shows that uncertainty is a common experience for long-term survivors of breast cancer. The most common sources of uncertainty among breast cancer survivors are new or unfamiliar symptoms, and the unpredictability of events, such as worsening symptoms that create fears of recurrence (Ferrell et al., 1996; Gray et al., 1998; Hilton, 1989; Polinsky, 1994). The fear of recurrence and corresponding uncertainty of older breast cancer survivors can be triggered by many circumstances. Among 241 older breast cancer survivors who were at least 5 years post treatment, Gil et al (2002) found that the average number of triggers of uncertainty about recurrence was 1.9 per month, illustrating the pervasiveness of uncertainty well beyond the initial diagnosis and treatment phase of illness. The most frequent triggers of uncertainty about recurrence were "hearing about someone else's cancer," new physical symptoms, environmental triggers such as sounds and smells, information in the media, and annual medical appointments. This study supports the work of Mast (1998b) who found that symptom distress and fear of recurrence explained 40% of the variance in uncertainty and were the strongest predictors of uncertainty, in older (mean age 60 years) breast cancer survivors who were free of recurrence and one to six years post treatment.

An identified problem with the literature on uncertainty in breast cancer survivors is a lack of conceptual clarity of the term survivor. Different operational definitions of when one becomes a survivor vary from 2 months (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Dirksen, 2000), 8 months (Boon, Brown, Gavin, Kennard, & Stewart, 1999), 1 year (Mast, 1998b; Johnson Vickberg, 2001; Sammarco, 2001b), 2 or more years (Nelson, 1996), to 5 years or longer (Mishel, 1999; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). Some researchers use the term long-term survivor to differentiate among women who have survived beyond 5 years from initial diagnosis and treatment (Halstead & Fernsler, 1994; Mishel, 1999) but other operational definitions of long-term survivor are used, such as 3 years (Loescher et al., 1990), or 4 years (Gray et al., 1998). Yet, there is evidence that the needs and concerns that cause uncertainty for breast cancer patients change as one moves farther away from the treatment phase (Hanson Frost et al., 2000). Other work among survivors living 5-29 years from diagnosis has found that the meaning of illness also changes as one moves further from diagnosis (Utley, 1999).

Additionally, the concerns of women may differ by age, despite similar length of survival (Ganz, Lee, Sim, Polinsky, & Schag, 1992). One early exploratory study investigating the impact of the cancer experience for long-term survivors included subjects with an age range from 25-80 years, and a survival time of 3-30 years (Loescher et al., 1990). Complicating the interpretation, this study combined eight types of cancer diagnoses, including breast cancer survivors (Loescher et al., 1990). While this study helped identify the global concerns of cancer survivors, it may not adequately represent the specific concerns important to older breast cancer survivors. Future studies of breast cancer survivors may benefit from stricter inclusion criteria that will facilitate enhanced comparison among findings pertinent to specific ages and/or length of survivorship.

The Influence of the Stimuli Frame on Uncertainty

According to the Uncertainty in Illness theory, a primary antecedent of uncertainty is the concept of stimuli frame (Mishel, 1988). Stimuli frame encompasses the symptom pattern, as well as the familiarity and congruity of experienced and anticipated events. When symptoms can be predicted, and recognized as repetitive, there is less ambiguity about the cause of illness. This allows patients to interpret the meaning of symptoms and form a predictable symptom pattern. Thus, when symptoms are predictable and familiar, patients are able to construct an individualized cognitive schema of events and uncertainty is reduced (Mishel, 1988). When symptoms are consistent with what was expected, they can be understood and managed.

When symptoms are unfamiliar, and when events do not occur as expected, uncertainty increases (Mishel, 1988; Mishel & Braden, 1988). This can result from ambiguous symptoms (Hilton, 1988; Wiener & Dodd, 1993), the onset of new symptoms or an inability to distinguish among symptoms (Mishel, 1988). For older breast cancer survivors it may be difficult to distinguish between normal aging processes and symptoms that may indicate a recurrence of breast cancer (Gil et al., 2002; Mishel & Braden, 1988). Additionally, in chronic illnesses such as multiple sclerosis that have periods of exacerbation and remission a pattern of symptoms is not always discernable, contributing to higher levels of uncertainty, and poorer adaptation to illness (Crigger, 1996; Wineman, Schwetz, Goodkin, & Rudick, 1996). Finally, the accuracy of symptom appraisal may contribute to an inability to discern a pattern among symptoms. Those who are depressed or anxious may incorrectly appraise and evaluate symptoms, contributing to higher levels of uncertainty (Mishel, 1988). Additionally it is possible that situational factors such as being sleep deprived or on certain medications may also contribute to an incorrect appraisal of symptoms. Thus normal life events may contribute to an inability to form a symptom pattern and therefore increase uncertainty for the older breast cancer survivor. For example, the older breast cancer survivor who has a co-morbid chronic illness and is on medication as well as experiencing symptoms of normal aging, or who may be emotionally upset or sleep-deprived from other situational events such as a spouse's illness, may have difficulty in correctly forming a symptom pattern and thus experience high levels of uncertainty about the recurrence of her breast cancer.

The Relationship Between Symptom Number and Uncertainty

The number of physical symptoms has been shown to impact uncertainty (Mast, 1998b; Mishel & Braden, 1988). Researchers report that women with multiple health complaints have higher levels of emotional distress and uncertainty (Bleiker et al., 2000; Mast, 1998b). Among breast cancer survivors, over 50% report the presence of physical symptoms due to original treatment for breast cancer, including arm problems such as limited range of motion, lymphedema, increased infections, fatigue, numb areas, and pain (Ferrans, 1994; Polinsky, 1994). More recent research estimates that as many as 84% of survivors experience some type of physical complaint as a result of their original treatment for breast cancer (Gil et al., 2002; Mishel et al., 2002). Gil et al. (2002) found that the most common symptoms reported by women over 50 and who were at least 5 years from original diagnoses and treatment, were fatigue, joint stiffness, and pain. These researchers found that 70-80% of women reported experiencing these symptoms during a six month period, with women reporting an average of at least one symptom per month (Gil et al., 2002). For older women, symptoms such as fatigue, limited range of motion or joint stiffness, and pain may be similar or identical to those of normal aging or common co-morbid conditions such as arthritis, creating the inability to form a symptom pattern and/or distinguish between breast cancer and other conditions, thus contributing to uncertainty.

Specific symptoms such as fatigue are particularly troublesome for breast cancer survivors. Fatigue is one of the most frequent symptoms in cancer patients in general (Okuyama et al., 2000), and is a major concern of older breast cancer survivors (Wyatt & Friedman, 1998). Indeed, one study found fatigue to be both the most prevalent and most burdensome side effect of treatment in a sample of 53 breast cancer patients up to 5 months post treatment (Longman, Braden, & Mishel, 1999). Fatigue has been found to explain a significant amount of the variation in uncertainty among breast cancer survivors, (Mast, 1998a). Mishel and colleagues (2002) found a high incidence of fatigue (83%) in a sample of older recurrence free women who were at least 5 years post treatment. Fatigue has been associated with concurrent illness as well as treatment modalities such as chemotherapy, irrespective of age, disease stage, tamoxifen use, or time from initial treatment (Mast, 1998a).

The Relationship Between Symptom Bother and Uncertainty

Physical symptoms impact a woman's daily life in a number of different ways such as an increased need for rest periods, the need to wear uncomfortable compression sleeves, the need to stay out of the sun, inability to wear certain types of clothing, and the potential for cuts during underarm shaving due to numb areas of the axilla (Bower et al., 2000; Polinsky, 1994). Additionally, the presence of physical symptoms may cause women to feel dependent on accessories such as scarves and wigs. When women experience constant reminders of their breast cancer due to the inability to resolve symptoms such as lymphedema, and the subsequent need to alter their lifestyle, these reminders can create continual uncertainty and fears of recurrence (Carter, 1997)

The Influence of the Stimuli Frame on Emotional Well-Being

The Relationship Between Symptom Number, Symptom Bother, and Mood State

Although the uncertainty in illness theory does not propose a direct relationship between symptom pattern and emotional well-being, there is some research that suggests support for this relationship between symptom pattern and emotional well-being. In a small sample of patients with chronic obstructive pulmonary disease, Small and Graydon (1992) found fatigue was directly related to increased emotional distress. In samples of cancer patients, cancer survivors of multiple types have reported that new or distressing physical symptoms are associated with emotional symptoms such as anxiety, as well as issues of inadequacy and self-esteem (Loescher et al., 1990; Mast, 1998b). Among breast cancer patients, negative psychological adjustment in the areas of negative feelings, sleep problems, depression and anxiety, have been associated with higher levels of symptom burden (Longman et al., 1999; Longman, Braden, & Mishel, 1996).

Specific physical symptoms have been linked to emotional distress. Carpenter et al. (Carpenter, Johnson, Wagner, & Andrykowski, 2002) found that hot flashes were associated with emotional distress, negative affect, and poorer quality of life for breast cancer survivors, while other research has associated fatigue with depression especially in those who received chemotherapy as part of their original treatment for breast cancer (Bower et al., 2000; Longman et al., 1996). Carter (1997) found that women reported distress when attempting to manage lymphedema with two subjects reporting severe depression related to their inability to manage this physical symptom. Many had tried several different treatments for lymphedema but were unable to resolve this problem.

The Relationship Between Symptom Number, Symptom Bother, and Troublesome Thoughts of Recurrence

The fear of recurrence is prevalent among older breast cancer survivors (Gil et al., 2002; Johnson Vickberg, 2001; McKinley, 2000; Wong & Bramwell, 1992). As previously discussed, new and unpredictable symptoms have the potential to cause fears of recurrence in breast cancer survivors. For example, lymphedema, which has an unknown date of onset potentially developing many years post treatment, is likely to cause fears of recurrence for breast cancer survivors. Even when women understand their symptoms and are managing them successfully on a daily basis, the constant reminder of breast cancer may still cause troublesome thoughts of the fear of recurrence and affect overall emotional well-being.

In a study investigating physical and emotional difficulties faced by 223 breast cancer survivors who were 16 months to 32 years post treatment, 89% of respondents admitted to fears of recurrence although there was minimal mood disturbance, indicating an emotionally healthy sample. The vast majority of women in this sample endorsed physical symptoms as a result of surgical treatment with the most prevalent symptoms being arm problems including numbness (Polinsky, 1994). Another large study of survivors age 50 and older, and 1-5 years post diagnosis, investigated the influence of type of treatment on physical and emotional outcomes of breast cancer including thoughts of recurrence. Forty percent of women in this study endorsed continual fears of recurrence. Findings showed that although there was no relationship between treatment modality on fears of recurrence or level of depression, women who underwent mastectomy experienced more long-term physical symptoms than those who had other types of treatment (Rowland et al., 2000). Additionally, in a large study of breast cancer survivors 5 or more years from original treatment and diagnosis, Mishel et al found a significant correlation between troublesome thoughts of recurrence and both the number of symptoms as well as the bother women attributed to reported symptoms (unpublished data, Managing uncertainty in older breast cancer survivors, NIH/NCI 5R01 CA 78955-03 P. I. Merle Mishel). Together, these studies suggest the potential for increased uncertainty and troublesome thoughts of recurrence from new and/or unpredictable symptoms in older survivors, especially those who undergo mastectomy.

The Influence of Structure Providers on the Stimuli Frame

The variable of structure providers is a seçond antecedent of uncertainty (Mishel & Braden, 1988; Mishel, 1988). Structure providers are resources that are available to patients to help them to explain and assign meaning to their symptoms and patterns of illness. Education, credible authorities such as healthcare providers, and social support systems, are considered to be structure providers (Mishel & Braden, 1988; Mishel & Clayton, in press). For this review credible authority is discussed from the perspective of the patient-provider relationship focusing on the amount of communication, level of patient involvement, and patient decision-making role.

The Relationship Between Education, Symptom Number and Symptom Bother

Although no research could be located directly investigating the impact of education on symptoms, it is generally accepted that cancer patients with a low level of literacy (used as a proxy for low level of education) have difficulty in understanding their symptoms, that may cause them to present with more advanced disease at diagnosis (Davis, Williams, Marin, Parker, & Glass, 2002). One study of cancer patients in North Carolina found that African American patients possess much less knowledge about the pervasiveness and benefits of early detection of cancer than Caucasian patients, even after controlling for age (Michielutte & Diseker, 1982). This study also found that African American patients prefer radio and television as sources of health information, while Caucasian patients prefer printed materials.

Low literacy levels may also adversely affect cancer communications between patient and provider about the risks and benefits of various treatment and symptom management options (Davis et al., 2002). Many patients complain that they do not understand the language used by healthcare providers (Lerman et al., 1993). For those with low levels of education, this problem may be even worse.

Some research suggests that reducing the disparity in education (and the corresponding disparities in income and employment) will do more to improve the overall health status of African Americans in the United States than reducing access to care disparities such as insurance coverage (Waidmann & Rajan, 2000). This is response to research suggesting that decreased access to care for African-American breast cancer patients contributes to increased mortality and morbidity for African-American breast cancer patients (Bibb, 2001; Hunter, 2000; Moormeier, 1996;

Underwood, 1999). Findings have shown that education accounted for 22% of the disparity in health status attributable to ethnic differences for African Americans who were in fair or poor health, while insurance coverage only accounted for 3% of this difference, suggesting that education plays a major role in the level of self reported health status for African Americans. For utilization of breast cancer screening, education accounted for the largest percentage (39%) of the difference attributable to ethnic differences for African American women, while again, insurance played a comparatively smaller role only accounting for 16% of the difference in utilization of screening attributable to ethnic differences.

Other data show that African American women are more likely to have advanced stage breast cancer at diagnosis, and have poorer 5-year survival rates than Caucasian women (Davis et al., 2002; Williams, 2002). Explanations for this disparity focusing on the socioeconomic status, (SES), indicators of education, income and occupation have not explained the majority of these observed differences, suggesting that the interaction of SES, ethnicity, and health status is a complex, not well understood process, as evidenced by continued health status disparities by ethnicity at all levels of SES, and the fact that these indicators explain only one half to one third observable differences in healthcare disparities (Williams, 2002).

The Relationship Between Symptom Number, Symptom Bother, and Credible Authority

A credible authority decreases uncertainty indirectly through the stimuli frame by reducing the complexity of symptom patterns and treatment issues (Mishel & Braden, 1988). A credible authority such as a healthcare provider assists the patient to explain and assign meaning to the illness experience by providing information, or by assuming control over the situation. This allows patients to give meaning to the stimuli frame by facilitating the understanding of events and symptoms. Thus, credible authority indirectly influences uncertainty through the stimuli frame, by assisting patients to understand and predict their symptoms and illness progression (Mishel, 1988).

Even when a credible authority such as a healthcare provider is knowledgeable about the concerns of patients, he or she can only provide needed information if the patient shares needs and concerns during the medical exchange. Unfortunately, there is evidence that when older women with breast cancer seek the advice of their provider in an effort to distinguish between benign and serious symptoms, they are reluctant to mention their symptoms for fear of being perceived as critical or ungrateful (Leigh, 1992). Similarly, Johnson et al (1996) found that although 76% of women with newly diagnosed breast cancer (mean age 54.6) had specific fears about their diagnosis, only half revealed these fears to their providers.

Other research suggests that women interact with providers differently than men (Gabbard-Alley, 1995; Verbrugge, 1985; Verbrugge, 1990). Studies show that women's concerns are taken less seriously, and their questions are either ignored or answered in a vague fashion (Patterson, Leonard, & Titus, 1992; Verbrugge, 1985; Verbrugge, 1990). Yet, the desire for information is well documented among breast cancer survivors (Wilson et al., 2000; Loescher et al., 1990; Ferrans, 1994; Polinsky, 1994). Girgis et al (2000) reported that breast cancer patients felt that two thirds of their unmet needs were related to their inability to obtain desired information. Yet, women report frustration and difficulty in locating information about common symptoms such as lymphedema, and find their providers to be equally unknowledgeable about this condition (Carter, 1997). In addition to information on physical symptoms, many breast cancer survivors want their provider to be knowledgeable about community support services, but again reported that their providers were unfamiliar with these services, further contributing to the inability to obtain information, and thus potentially increasing uncertainty, on how to adapt to being a breast cancer survivor (Wilson et al., 2000).

Many women approach the medical encounter from a contextual, socio-emotional perspective, in contrast to the biomedical perspective of most physicians (Borges & Waitzkin, 1995; Gabbard-Alley, 1995; Korsch, Gozzi, & Francis, 1968). This incongruence in approach may contribute to the patient perception that emotional and physical concerns are trivialized and that the provider does not value or perceive her concerns as worthy of attention. Paget's (1983) analysis of a medical exchange between a woman with cancer and her physician provides an example of how physicians may redirect, avoid, and/or trivialize concerns that they don't wish to manage or understand. The result of this interchange illustrate how the provider created a totally different cause and meaning of the illness experience than what the woman was trying to convey and additionally raises ethical concerns about informed consent and patient autonomy.

In other research, some women felt that their concerns about lymphedema were trivialized by their providers, and report being told that they "should be thankful to be alive and [should] just learn to live with it" (Carter, 1997), creating anger and frustration. The devaluation of a woman's needs and concerns is supported by the work of Mann and colleagues (2001) who suggested this explanation for the decrease in satisfaction with providers reported by older women when compared to older men. Thus, the fact that the vast majority of breast cancer survivors are women may affect their ability to have male providers take their concerns and symptoms seriously.

The Modifying Effects of Age and Ethnicity

Introduction

To date, most of the research involving breast cancer survivors has been among educated, affluent, Caucasian women (Meyerowitz et al., 1998; Leedham & Ganz, 1999). Research on African-American breast cancer survivors is much more limited despite the fact that breast cancer remains the most common cancer among African-American women, and 5 year survival rates for African-American women have increased to 72%, although these rates are still lower than for Caucasian women (American Cancer Society , 2002; American Cancer Society, 2000).

The importance of exploring the issues faced by African-American women is just recently being recognized. Investigators examining breast cancer in African-American women have explored quality of life, finding that as in Caucasian women, increased symptom burden contributes to a lower quality of life (Northouse et al., 1999); psychosocial adjustment, finding that those who had less than a high school education had poorer adjustment to the breast cancer experience (Beder, 1995); and body image including sexuality, finding that although concerns are similar to Caucasian women, they are not identical in terms of ideal body image and sexuality (Wilmoth & Sanders, 2001; Wyatt et al., 1998). Qualitative research by Moore (2001) suggests that African American women perceive breast cancer to be a disease of Caucasian women, and that they feel that their unique concerns have been largely ignored. Yet, Farmer and Smith (2002) in their concept analysis of survivorship, note how little literature relates directly to the meaning of breast cancer survivorship among African American women, in fact they only mention two studies that explore this specific concept in African-American women. Noting that most of the survivor literature has been among Caucasian and middle class women, Farmer and Smith (2002) have hypothesized that the experiences of survivorship among African American women may differ by different from those of Caucasian women, and further that African American women may differ by Socio-economic status in their experiences of survivorship.

Another interesting issue is raised by Bourjolly (1998) in a comparison of Caucasian and African American breast cancer survivors 3.8-5.8 years post treatment. African American women scored higher on both private and public measures of religiosity, and historically viewed God as a healer and protector in times of severe distress. Results showed that African American women rely on religiousness as a coping resource more than Caucasian breast cancer survivors (Bourjolly, 1998). Thus, these researchers conclude by asking: If God is viewed as a healer, do African American women simply not need healthcare providers? Further, do these women see medical and religious interventions as separate, or as two parts of a unified treatment plan to assist in the reduction of symptoms and the management of illness? While no answers are offered to these provocative questions, it does raise the question of the importance placed on the patient-provider relationship by African-American women, and how this relationship affects the patient perception of symptom burden, uncertainty, and emotional well-being.

In related work, Ashing-Giwa and Ganz (1997) note that the word cancer still evokes tremendous fear in African-American communities and may even be taboo in some segments of the community. Qualitative work by Moore (2001) further suggests that African American women view a diagnosis of breast cancer as a death sentence, not appreciating the current advances in treatment and prevention, and therefore may be reluctant to discuss treatment options with healthcare providers. Supporting this, Powe (1996) suggests that African American may believe that they can do nothing to modify their disease process once they have been diagnosed with cancer, and believe that that their fate is inevitable, thus under-utilizing medical care and medical screening opportunities. These studies, and the work by Bourjolly (1998) demonstrating reliance on religiosity, further support the issues raised by Farmer and Smith (2002), suggesting that the experience of survivorship may be very different in African American women as compared to Caucasian women. It remains to be discovered if age or education influence these cultural beliefs.

Among older African-American breast cancer survivors, investigators have recently evaluated differences in the triggers of uncertainty between 171 Caucasian and 73 African-American women over age 50 related to the fear of recurrence, finding that overall, the most commonly reported trigger of uncertainty about recurrence was "hearing about someone with cancer" (Gil et al., 2002). However when examined by ethnicity, African American women reported that "new symptoms" was the more frequent trigger of the fear of recurrence while Caucasian women reported that "hearing about someone with cancer" was the most frequently occurring trigger. Moreover, significantly fewer African American breast cancer survivors experienced environmental triggers, and triggers related to controversial discussions of breast cancer offered in the media than Caucasian women (Gil et al., 2002). Although both African American and Caucasian women reported that attention by healthcare providers to experienced symptoms was a trigger of the fear of recurrence, it was reported by the fewest number of women regardless for both African-American and Caucasian women (Gil et al., 2002).

Gil et al (2002) reported that ethnicity had no effect on the frequency of reported symptoms. Fatigue was the most frequently reported symptom, followed by joint stiffness, pain and lymphedema (Gil et al., 2002). These findings of ongoing symptoms due to late emerging treatment side effects support other research reporting the overall symptom burden in breast cancer survivors irrespective of ethnicity (Mast, 1998a; Bower et al., 2000; Northouse et al., 1999; O'Hare et al., 1993; Paci et al., 1996; Hull, 2000).

The Effect of Ethnicity on the Relationship Between Symptom Number, Symptom Bother and Education

No studies were located that discussed the modifying effect of ethnicity on the relationship between education on symptoms. However, as previously discussed, those persons with lower literacy levels may have difficulty in interpreting the significance of their cancer symptoms as well as difficulty with discussions about the management of these symptoms (Davis et al., 2002). Further, national data show that among women born in 1946-1951 (currently age 52-57) only 60.5% of African Americans as opposed to 80.5% of Caucasians have completed high school (U.S. Department of Education , 2002). It is therefore reasonable to assume that ethnicity may moderate the relationship between education and symptom pattern. However, qualitative work by Ashing-Giwa and Ganz (1997) found that those African-American women with more education had more understanding of the benefits of early detection and treatment, as well as the possibility of cure if breast cancer is detected early, than those with lesser amounts of education.

The Effect of Age on the Relationship Between Symptom Number, Symptom Bother and Education

Although no studies were located assessing the impact of age on the relationship between education and symptoms in older breast cancer survivors, based on a review of existing communication and cancer literature it is thought that the literacy level of cancer patients (reflective of educational attainment) impacts understanding of cancer symptoms and their subsequent treatment (Davis et al., 2002). It is also known that age impacts level of education as demonstrated by the knowledge that 10% more people born 1983 or later completed high school than who were born in 1946 (U.S. Department of Education , 2002). This is supported by the work of Steptoe (1991), who found that age was inversely correlated with education in a sample of 77 hospitalized cancer patients and further, that older persons scored less well on tests of general medical and cancer knowledge. Thus, it is reasonable to assess the impact of age on the relationship between education and symptom pattern.

The Effect of Ethnicity on the Relationship Between Symptom Number, Symptom Bother, and Credible Authority

It is known that the impact of physical symptoms may be influenced by individual characteristics such as ethnicity. For African-American women these differences revolve around the interpretation and meaning of physical symptoms such as the presence of keloids, hair loss, and ideal body image (Baturka et al., 2000; Wilmoth, 2001; Wilmoth & Sanders, 2001). Gotay and colleagues (Gotay, Holup, & Pagano, 2002) examined the influence of ethnicity among 227 newly diagnosed prostate (N=101) and breast cancer (N=126) patients, of Filipino, Native Hawaiian, and Japanese ethnicities, finding ethnic differences in both number of physical symptoms and ultimate quality of life. However, findings by Ashing-Giwa (1999) and associates, in a sample of African-American and Caucasian long-term breast cancer survivors, do not support Gotay's research. These investigators found that when demographic variables were controlled, ethnic differences among Caucasian and African-American women disappeared (Ashing-Giwa et al., 1999).

Investigators exploring the impact of ethnicity on health communication in general have found that Caucasians often receive more total communication than non-

Caucasians (Roter, Hall, & Katz, 1988). Early research by Starr (Starr, 1982) found that persons of different ages and ethnicities receive differing amounts of care and amounts of information from physicians. When one considers that a primary role of the healthcare provider is to provide information during the process of patient-provider communication, and that minorities may receive less information than Caucasians, it is possible that this lack of information for minority patients has the potential to affect the ability to understand and predict symptoms. Additionally, when information is not offered, the ability to make treatment decisions about symptoms is hampered.

Decision-making.

Among breast cancer survivors in general, decision-making has been reported as an essential component of patient-provider communication, however, there have been no studies of the adopted or preferred decision-making role among older African-American breast cancer survivors (Crooks, 2001)(Degner, L. personal communication 4/2002). Thus, the preferred decision-making role with respect to symptoms and treatment is yet another area where the information is needed to adequately address the concerns of older African-American breast cancer survivors.

It is reasonable to hypothesize that the impact of the patient-provider relationship on a woman's ability to manage her symptoms and the associated uncertainty for older breast cancer survivors may be different for African-American and Caucasian women. There is evidence that African-American patients perceive that they have less participation in the medical exchange than Caucasian patients. In a racially balanced study of 1,816 patients age 18-65 in 32 urban primary care settings, Cooper-Patrick and colleagues (1999) reported that African-American patients rated their visits as significantly less participatory in terms of shared decision-making than Caucasian patients, after adjusting for age, gender, education, health status, marital status, and length of the patient-provider relationship. In a related study, Moore (2001) reported that African-American breast cancer survivors felt uninformed about.the risks of treatment at the time of diagnosis. African-Americans, especially older less educated African-Americans, may view the healthcare system and providers with distrust due to documented mistreatment, yet still view the provider as having the ultimate authority or power in the patient-provider relationship (Guillory, 1987; Meyerowitz et al., 1998). While this may contribute to how decisions about symptoms and late treatment side-effects are actually made during visits with their healthcare provider, it does not reflect the desired decision-making role of these women.

The Effect of Age on the Relationship Between Symptom Number, Symptom Bother, and Credible Authority

Age is thought to moderate the relationship between the patient-provider relationship and the stimuli frame in older breast cancer survivors by influencing the symptoms a woman experiences, as well as how these symptoms are interpreted and managed. As age increases, so do the number of symptoms experienced and managed. Yet women may be unable to distinguish whether or not these symptoms are a result of breast cancer treatment or another condition, for example, shoulder or arm stiffness and pain that is due to lymphedema versus arthritis (Morrow, 1994).

When studies of older patients have investigated information-seeking practices of patients, findings show that older patients in general report receiving less information from providers, and are reported to be less comfortable with question asking (Comstock, Hooper, Goodwin, & Goodwin, 1982; Greene, Adelman, Charon, & Hoffman, 1986). Additionally, because symptoms and concerns are different between older and younger women, the type of information desired by older women may be different than that sought by younger women (Anllo, 2000; Degner et al., 1997b). In a large study of 1,012 breast cancer patients, Degner and Kristjianson (1997b) found that women over 70 were more interested in information about self care while younger women were more interested in information about physical and sexual attractiveness. In contrast, Annlo (2000) found that women of all ages were concerned with the effects of treatment on sexual attractiveness, however younger women were more concerned about the effects of treatment on fertility, and fear of abandonment by a spouse, than older women.

Although research demonstrates that older persons often receive less information, older patients have reported that they desire as much information about symptoms and illness as younger patients (Turk-Charles et al., 1997). A study by Turk-Charles et al. (1997) among 75 patients with mixed cancer diagnoses (age 18-81) investigated the role of age with respect to information seeking, finding that there was indeed a general decrease in information-seeking from medical establishments as age increased. However, older adults sought more information than younger adults from non-medical sources when the desire for information was high (Turk-Charles et al., 1997).

Another study investigating the information seeking behaviors of older patients showed that information may be better understood when presented differently for older versus younger patients, due to limitations commonly experienced by older persons such as hearing, vision, and cognition (Hayes, 1998). Additionally, it has been shown that many office visits last less than 18 minutes, yet more information- seeking and shared decision-making behaviors among older patients has been reported in visits exceeding 20 minutes (Beisecker & Beisecker, 1990; Kaplan, Gandek, Greenfield, Rogers, & Ware, 1995). Therefore, older persons may be frustrated and left with unanswered questions about their symptoms at the close of these shorter medical exchanges.

An additional problem in assessing the influence of age among breast cancer survivors is the lack of consensus of the definition of older, making the interpretation of studies difficult. The wide range of definitions of the word older in the literature has defined older women as 50 years or older (Mishel et al., 2002), 60 or more years (Cameron & Horsburgh, 1998; Greene, Adelman, Friedmann, & Charon, 1994), 65 years (Gollop, 1997), and 66 years and older (Crooks, 2001). Yet, the needs, concerns, and symptoms of women can be very different depending on their age (Ganz et al., 1992; Sammarco, 2001a). For example, Mast (1998b) found that older age (mean age 60 years) was associated with less fear of recurrence in survivors, while Ganz and associates (1992) investigated the effects of age among 229 newly diagnosed women (mean age 55.2 years), finding significant differences in medical and treatment variables.

The fact that age is associated with menopausal status may affect the issues and concerns that women want to address in the medical exchange. For younger women chemotherapy and adjuvant hormonal therapy may be associated with earlier than anticipated menopause (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Wilmoth, 2001). For older women a diagnosis of breast cancer may require the cessation of previous hormone replacement therapy (Meyerowitz et al., 1999). Both these situations, as well as the impact of chemotherapy may cause treatment related side effects affecting sexuality and intimacy, yet concerns are different for older versus younger women, such as fertility concerns and vaginal dryness (Anllo, 2000; Degner et al., 1997b; Ganz et al., 1998). However, it is difficult to extrapolate the needs of older women from data collected from younger women. Silliman and colleagues (1993) noted that none of the clinical trials supporting the 1990 National Institutes of Health Consensus Development Conference on Treatment of Early-Stage Breast Cancer Guidelines included older women, despite the fact that breast cancer is known to be a disease of older women (American Cancer Society, 2001a).

Decision-making.

The desire for involvement and the preferred decision-making role varies with individual characteristics as well as disease trajectory. In general, predictors of the desire to participate show that older, sicker, less educated patients, and minority patients, prefer a more paternalistic (or provider centered) model of patient-provider interaction (Ende et al., 1989; Degner & Sloan, 1992; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988). However, overall, age has been found to be the best demographic predictor of the desire for participation in the medical exchange (Degner & Sloan, 1992; Ende et al., 1989). In a study of 436 newly diagnosed cancer patients Degner and Sloan (1992) reported that 91% of patients over 50 years old preferred a passive role or collaborative decision-making role, with only 10% preferring to actively make decisions. In contrast, only 79% of patients under age 50 preferred a passive or collaborative role, while the percentage of patients preferring an active role more than doubled (Degner & Sloan, 1992). Yet, the researchers noted that socio-demographic variables only accounted for 15% of the variance in the amount of preferred control in treatment decision-making (Degner & Sloan, 1992). This study demonstrates that the overwhelming majority of patients over 50 years old desire a passive or collaborative decision-making role in the patient-provider relationship. This is in direct opposition to earlier findings which concluded that the majority of patients wish to be more actively involved in their care (Cassileth et al., 1980; Ende et al., 1989). Nevertheless, it is important to note that this study included patients with multiple types of cancer diagnoses, and may not represent the specific desires of older breast cancer survivors. Unfortunately, despite the majority of patients desiring some level of participation, research shows that often women with breast cancer are not given sufficient information about symptoms occurring after treatment to allow them the level of participation that they desire, especially in the years following treatment (Suominen, 1992). For other women, lack of choice during original treatment decision-making may create lasting concerns related to body image and appearance, especially in unpartnered women (Ganz et al., 1998).

Kaplan and associates (1995) investigated the patient's perspective of how willing their provider was to involve them in decision-making, finding that those who were over 75 years or under 30 years experienced the least participatory visits, even after controlling for the length of the visit. A goal of this study was to discover if there was an "at risk" profile of patients who are unable to elicit a mutual decision-making style of communication from their physician that, in turn, might affect health outcomes. Another study, exploring the influence of age on initial treatment decision-making among newly diagnosed women with breast cancer, reported that as age increased, women were offered fewer choices of treatment and spent less time engaging in decision-making with their provider (Crooks, 2001). Crooks (2001) also found that no woman over the age of 80 had been given a choice of treatment.

While research suggests that older breast cancer patients are given less information and choice of treatment, increasing age in this population has been shown to be a predictor of the desire for more choices and involvement (Johnson et al., 1996). Johnson and associates (1996) found that younger breast cancer patients were more likely to want their provider to suggest a course of treatment, while older women desired more collaborative relationships with their providers and were more comfortable making independent treatment choices. Qualitative work by Crooks (2001) found that only 2 of 20 women thought their surgeons should make the decision for them, in a sample of women age 66-94 who were diagnosed after age 65. In a review of the literature, Silliman et al. (1993) note the lack of evidence on what constitutes effective treatment for older women, as opposed to better studied younger women, concluding that providers can best serve older women by including them in the decision-making discussions of treatment choices, issues, and follow-up care. Yet, despite the known desire of older women to participate, and suggestions that clinicians should involve older women in decision-making, studies report that less than 50 % of breast cancer patients achieve their desired decision-making role in the medical exchange (Beaver et al., 1999; Degner et al., 1997b). This creates frustration in women who desire participation in decision-making about their symptoms and treatment side effects as they attempt to manage symptoms without the necessary knowledge, and may reflect providers tendencies to minimize late treatment side effects (Carter, 1997; Girgis et al., 2000b; Mann et al., 2001).

This evidence suggests that what older breast cancer patients' desire may be the opposite of what often happens in the medical exchange. The recent findings with older breast cancer patients contradict earlier studies suggesting older age in general as a predictor of preference for less participation in decision-making in the patient-provider relationship (Cassileth et al., 1980). Although a discussion of decision-making preferences among patients with different types of cancer diagnoses is not within the scope of this study, this finding may be partially explained by noting that the difference in findings has occurred between studies that specifically investigate the preferences of older women with breast cancer versus studies that have samples composed of mixed cancer diagnoses and age groups.

The Influence of Structure Providers on Uncertainty

Theoretically, structure providers may directly reduce uncertainty by providing information (Mishel, 1988). The role of structure providers in reducing uncertainty has been supported in both seriously ill patients and parents of seriously ill children (Bennett, 1993; Mishel & Braden, 1988; Santacroce, 2000; Tomlinson, Kirschbaum, & Anderson, 1996).

The Relationship Between Education and Uncertainty

Empirical support for the role of education in reducing uncertainty is unclear. Education is thought to reduce uncertainty through greater experience and knowledge thus allowing patients to havegreater understanding of their illness and treatment (Mishel, 1997). Education has been found to reduce uncertainty in cardiac patients during the acute treatment phase of illness (Christman et al., 1988), in gynecological cancer patients (Mishel, Hostetter, King, & Graham, 1984), and in breast cancer survivors for as long as 1-20 years post treatment (Hilton, 1994; Mast, 1998a; Wonghongkul et al., 2000). However, the relationship of higher education to lower uncertainty is not supported in a study of patients with varying medical diagnoses, (Mishel, 1984), for breast cancer patients two weeks after mastectomy (Wong & Bramwell, 1992), or among men with colon cancer (Galloway & Graydon, 1996). In a nursing intervention designed to assist 177 women in managing the uncertainty associated with menopause, there was no relationship between levels of uncertainly and education either pre or post intervention, although age and level of previous knowledge were found to predict uncertainty pre-intervention (Lemaire & Lenz, 1995). Since the impact of education on uncertainty remains unclear, the direct relationship between education as a structure provider and uncertainty were tested in this sample of older breast cancer survivors.

The Relationship Between Credible Authority and Uncertainty

A direct effect of the patient-provider relationship on uncertainty has been theoretically suggested and empirically supported (Mishel, 1988; Mishel & Braden, 1988). When patients prefer a more passive role in the patient-provider relationship, preferring to delegate responsibility to the provider, uncertainty is thought to be reduced when the healthcare provider is viewed as trustworthy and competent (Mishel, 1988; Mishel & Braden, 1988). Obtaining information from a credible authority such as a healthcare provider may also reduce uncertainty and facilitate decision-making by expanding understanding of treatment alternatives (Molleman et al., 1984). Molleman (1984) found that consulting healthcare providers was effective in managing the uncertainty of cancer among 418 patients of varied cancer diagnoses. In uncertainty in illness theory, the provision of information is thought to be a major factor in reducing uncertainty by enhancing the familiarity and predictability of events and symptoms (Mishel, 1997). Therefore healthcare providers have been reported to directly reduce patient uncertainty via the trust and confidence patients have in their provider, and in the information obtained from the provider (Mishel, 1997; Mishel, 1988).

Conversely, the patient-provider relationship may contribute to increased uncertainty when patients have communication difficulties. Lerman and colleagues (1993) found that 84% of 97 breast cancer patients reported communication difficulties with providers. Common problems were not understanding the provider and a desire for more control in medical decision-making. However, it should be noted that subjects were predominately (95%) Caucasian and half were under age 54, and as such, not representative of African American or older breast cancer survivors (Lerman et al., 1993). Similarly, communication difficulties consisting of inadequate information from providers and insensitive remarks made by providers were reported to increase parental uncertainty (Cohen, 1995b).

Influences on Emotional Well-Being

The Influence of Uncertainty on Emotional Well-Being

The relationship of uncertainty to emotional well-being has been found to be important in patients of varying ages and types of diagnoses. The positive association between uncertainty and emotional distress has been found to be consistent in the literature. This association has been reported in samples with HIV (Brashers, Neidig, Reynolds, & Haas, 1998), pre-operative orthopedic patients (Calvin & Lane, 1999), parents of medically fragile children including those with cancer (Cohen, 1995b; Cohen, 1995a; Grootenhuis & Last, 1997), patients who undergo genetic testing for Huntington's Disease (Decruyenaere et al., 2003), as well as those with end stage renal failure (Gudex, 1995) and multiple sclerosis (Kroencke, Denney, & Lynch, 2001; Wineman, 1990). Landis (1996) found that uncertainty explained 43% of the variance in reduced psychological well-being in a sample of 94 patients with diabetes. However, in a small study of 26 patients with chronic obstructive pulmonary disease (Small & Graydon, 1993) this relationship was not supported.

A large amount of the research testing the association between uncertainty and emotional well-being has been done in cardiac populations (Bennett, 1993; Christman et al., 1988; Davis, 1990; Fleury, Kimbrell, & Kruszewski, 1995; Hawthorne & Hixon, 1994; Webster & Christman, 1988; White & Frasure-Smith, 1995; Carroll, Hamilton, & McGovern, 1999). In hospitalized cardiac patients of mixed diagnoses, uncertainty was found to predict emotional distress during hospitalization and for up to 4 weeks post discharge (Christman et al., 1988). Similar findings were reported by Davis (1990) in a mixed sample of hospitalized patient's recovering from acute traumatic injuries and cardiovascular conditions. Additionally, emotional distress has also been shown to result from uncertainty post angioplasty and post bypass surgery (White & Frasure-Smith, 1995) as well as in patients with heart failure (Hawthorne & Hixon, 1994). Heart failure patients in particular have been shown to have higher levels of mood disturbance due to complicated medication schedules, as well as frequent office visits and hospitalizations (Hawthorne & Hixon, 1994). This treatment complexity, necessitating the involvement of family members, and the inability to predict an illness trajectory resulting in ambiguity, has a greater influence on quality of life as opposed to patients with other types of cardiac diagnoses (Hawthorne & Hixon, 1994). Findings from this research show that the level of uncertainty, especially ambiguity (measured by the Mishel Uncertainty in Illness Scale, MUIS) significantly impacted all domains of mood disturbance (measured by the Profile of Mood States, POMS), complexity of care impacted quality of life, and finally, total uncertainty scores were associated with total mood disturbance scores. These researchers conclude that the level of uncertainty related to a patient's understanding of illness and level of involvement in care may explain levels of mood disturbance in this sample (Hawthorne & Hixon, 1994).

In cancer populations, the same relationship between higher levels of uncertainty and increased emotional distress has been supported. Germino et al (1998) found that uncertainty was inversely related to psychological adaptation among 403 African-American and Caucasian men with prostate cancer and their family care givers. Similarly, Christman (1990) found that uncertainty was associated with poorer psychological adjustment to the illness experience among patient's receiving radiation.

The direct relationship between uncertainty and emotional well-being has also been reported in women with breast cancer (Braden, Mishel, & Longman, 1995; Deane & Degner, 1998; Gil et al., 2002; Mast, 1998b; Northouse et al., 1995; Silberfarb, 1984;

Wong & Bramwell, 1992). Addressing the direct relationship between uncertainty and emotional adjustment, Braden and colleagues (1998) designed a self help intervention for women undergoing breast cancer treatment. The intervention addressed cancer knowledge, uncertainty management skills, and information concerning commonly experienced symptoms. Findings showed that women who participated in the self help intervention had better psychological adjustment and lower uncertainty than those who did not receive the intervention in a sample of 193 women undergoing treatment for breast cancer (Braden et al., 1998).

For women post-treatment, uncertainty remains related to emotional well-being. Breast cancer survivors commonly experience emotional symptoms such as anger, anxiety, and self esteem issues (Polinsky, 1994; Loescher et al., 1990; Dorval et al., 1998). Uncertainty about how to manage symptoms of disease and side effects for treatment has been found to predict levels of both depression and anxiety, influencing a woman's ability to adapt to and manage breast cancer (Hilton, 1988). Additionally, uncertainty about the future, including the fear of recurrence, influences emotional well-being in breast cancer survivors (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Nelson, 1996).

Among older breast cancer survivors, uncertainty related to the physical and emotional demands of living with a life threatening illness has been found to influence emotional well-being in 298 women over the age of 40 years. (Ferrell et al., 1998). These women cited the particular physical demands of fatigue and pain, and the specific emotional concerns of fears of recurrence and anxiety as being especially burdensome as well as causing uncertainty about the future that affected their overall quality of life. Similar findings were found in 101 younger breast cancer survivors age 31-49, showing that there was a negative correlation between uncertainty (measured with the MUIS) and quality of life, defined as a sense of well-being (measured with Ferrans and Powers Quality of Life Index- Cancer version) (Sammarco, 2001b).

The influence of Structure Providers on Emotional Well-Being

Uncertainty in Illness Theory does not suggest a direct association between structure providers and adaptation to illness, however some research has suggested that the structure providers (education, and credible authorities such as healthcare providers) may directly influence emotional well-being. Research supporting a direct relationship between education and emotional well-being is provided by the work of, Wineman and colleagues (Wineman et al., 1996) who explored predictors of emotional well-being (defined in this research as hopefulness and mood state) and uncertainty in 59 multiple sclerosis patients, finding that education was a major predictor of emotional well-being.

Examining the direct relationship between healthcare providers, specifically patient-provider communication, and psychological adjustment to illness, Steptoe and colleagues (Steptoe et al., 1991) found that hospitalized cancer patients who were more satisfied with the communication about tests, symptoms and treatment reported less anxiety than those who were less satisfied with the information given to them by providers. Additionally, Lerman and colleagues (1993) discovered that 84% of women (N=97) immediately post initial treatment for breast cancer had difficulty in communicating with their healthcare providers, especially those women who were less assertive. This difficulty in communication was associated with increased levels of anger, depression, confusion, and anxiety, persisting up to 3 months post initial treatment. These researchers noted the importance of efforts to improve communication between patient's and their healthcare providers as a means of enhancing mood state and emotional well-being in women with breast cancer (Lerman et al., 1993).

Conversely, Frost et al (2000) found that women with breast cancer who had experienced recurrence reported more difficulty in communicating with providers than women with breast cancer who had stable disease, recurrent disease, who were newly diagnosed, or receiving adjuvant therapy. Yet, these researchers did not find any differences in the psychological adjustment of these women (Hanson Frost et al., 2000).

Rutter and colleagues (1996) reported on an intervention directed towards improving oncologist's communication skills as a means of reducing anxiety and depression in cancer patients. Lung and breast cancer patients with a mean age of 57 years who interacted with trained providers reported lower levels of depression and anxiety, as well as increased feelings of control (Rutter et al., 1996).

The Mediating Influence of Uncertainty on the Relationship Between Structure Providers on Emotional Well-Being

Uncertainty in illness theory suggests that structure providers (such as education and healthcare providers) can directly affect uncertainty, and that uncertainty will then influence psychosocial adaptation to illness (Mishel, 1988). Supporting the theoretical interaction between structure providers, uncertainty and emotional well-being, Wineman (Wineman, 1990) found that uncertainty mediated the relationship between the structure provider of social support and emotional well-being in multiple sclerosis patients, although this relationship was not evaluated for the structure providers of education and credible authorities in this path model. With respect to education as a structure provider, no studies were located that assessed the interaction of education, uncertainty, and emotional well-being.

The mediating influence of uncertainty on the relationship between a credible authority as structure provider with emotional well-being, has been assessed by a small number of researchers. Among parents of children with chronic life threatening illness, Cohen (Cohen, 1995b) used a grounded theory approach to assess the triggers of parental uncertainty and anxiety. She found that healthcare providers who thoughtlessly used words that might indicate a relapse of the child's condition, or who did not communicate the results of testing in a timely fashion, triggered uncertainty in parents and contributed to heightened parental anxiety and distress. Similarly, Brashers et al (1998) describe how patient uncertainty may negatively affect adaptation to this disease due to interactions with providers who are not familiar with the rapidly evolving treatment protocols for persons with HIV. In women who had a benign breast biopsy, the uncertainty created due to not knowing a diagnosis and waiting for providers to communicate test results has also been shown to create anxiety (Deane & Degner, 1998).

In other work investigating the interaction between credible authorities, uncertainty and emotional outcomes Molleman et al (1984) found that expert help (a credible authority such as a healthcare provider) was important for the reduction of uncertainty among 418 cancer patients but did not subsequently reduce anxiety, rather, the support of family and other patients was more influential in reducing anxiety. However, among breast cancer survivors at least 4 years from treatment, Gray and colleagues (1998) reported findings from focus groups, demonstrating that women are uncertain about how to manage treatment related side effects such as lymphedema due to an inability to obtain consistent and complete information from providers, resulting in frustration, anger, and anxiety. These women also experienced frequent fears of recurrence impacting their emotional well-being as a result of increased uncertainty and an inability to obtain consistent information from their healthcare providers (Gray et al., 1998). Taken together, these studies with one exception (Molleman et al., 1984), demonstrate the influential role of providers on the level of uncertainty, and the subsequent impact on emotional well-being for patients with many types of illnesses, including breast cancer survivors.

Summary

Breast cancer survivors experience fears of recurrence and uncertainties that contribute to emotional distress. These symptoms and concerns are affected both by the age of the woman as well as ethnicity. When women turn to healthcare providers for information on managing their illness experience and the late emerging side effects of treatment, they are often frustrated in their attempts to convey their concerns and find resolution to their symptoms. This frustration may increase uncertainty and can impact a woman's emotional well-being, especially mood state. The result can be hopelessness, anxiety, and depression.

CHAPTER THREE: RESEARCH DESIGN AND METHODS

Purpose and Design

The purpose of this study was to test a conceptual model of emotional well-being in older breast cancer survivors. This model is presented with operational definitions in Figure 3. Guided by Mishel's Uncertainty in Illness Theory (1988), variables were selected for inclusion based on an intensive and systematic literature search showing that breast cancer survivors experience frequent late treatment side effects and fears of recurrence that often remain unaddressed. The resulting uncertainty about how to manage new or existing symptoms has been reported to cause both depression and anxiety in this population, however the patient-provider relationship as well as actual patient-provider communication may also be influential, affecting the level of reported uncertainty and subsequent emotional well-being in these women.

Sample and Setting

African American and Caucasian subjects from the control groups of three separate studies constituted the sample for this proposed research. The largest number of subjects was obtained from an ongoing intervention study, "Managing Uncertainty in Older Breast Cancer Survivors" (NIH/NCI 5R01 CA 78955-03 P. I. Merle

Mishel). This study will subsequently be referred to as Study 1. The control group of this large study is composed of newly recruited, recurrence free, women over age 50, who are at least 5 years from diagnosis and treatment.

The UNC School of Medicine granted original human subjects (Institutional Review Board) approval for Study 1. Newly recruited women were identified as eligible for inclusion from tumor registries across North Carolina. Recruitment procedures consisted of an introductory letter and a phone call made by a trained recruiter. Telephone calls were made to ascertain interest in the study, and verify eligibility criteria consisting of age 50 or older, no recurrence, African-American or Caucasian, and ability to pass the mini-mental status exam (Folstein, Folstein, & McHugh, 1975). There are 577 newly recruited women in Study 1 enrolled from 2,121 women originally identified as eligible. To maintain the interest and enthusiasm of these women, retention procedures consisted of special occasion cards and small monthly gifts due to the long period women remain enrolled in this study. These gifts served the additional purpose of allowing frequent updates of contact information. Analysis of baseline data from Study 1 revealed no differences between the experimental and control groups on variables selected for this analysis for these women.

Additional subjects were obtained from the control group of a previous intervention study of *older* Caucasian and minority women undergoing treatment for breast cancer: "Managing Uncertainty: Self Help in Breast Cancer" (NCI R01 CA 57764-04, P. I. Merle Mishel). This study were referred to as Study 2. As part of a planned follow up of these women, women from Study 2 were contacted and enrolled in Study 1 when they reached a minimum of 5 years from their original treatment thus meeting the inclusion criteria of Study 1, an ongoing long-term survivor study.

Original identification of eligible subjects for Study 2 was accomplished through contacts with healthcare facilities in North Carolina and Arizona, advertisements in local newspapers, and community workers who spoke to women at community group meetings. Additionally posters were located in businesses and churches to advertise the study and presentations were done at local health fairs. Only Caucasian and African-American women were recruited in North Carolina. This study drew upon the women recruited in North Carolina, not those who were recruited in Arizona. The final sample for Study 2 consisted of 210 women recruited in North Carolina (106 Caucasian, 104 African-American) and an additional 95 Mexican-American women recruited in Arizona who were not eligible for this study. The women were all age 50 and older, and were undergoing treatment for breast cancer at the time they were originally recruited.

The last group of subjects was obtained from the control group of another previous intervention designed for *younger* women receiving breast cancer treatment: “Promoting Self-Help: Underserved Women with Breast Cancer” (R01 CA 64706 02, P. I. Carrie Braden). This study will be referred to as Study 3. Women from Study 3 were contacted and enrolled in Study 1 as part of a planned follow-up of these women when they reached a minimum of 5 years from their original treatment and became age 50 or older, meeting the inclusion criteria of Study 1.

Original identification of eligible subjects for Study 3 was accomplished by referral from health care facilities in North Carolina and Arizona. Only African-American women were recruited in North Carolina. This study drew upon the women recruited in North Carolina, not those who were recruited in Arizona. In addition to referrals from healthcare facilities, the study was advertised in community groups and churches. Inclusion criteria consisted of receiving current treatment for breast cancer with no other concurrent treatment for cancer and under age 50. No restrictions were placed on disease burden, metastases or recurrence. The final sample in North Carolina consisted of 102 African-American women undergoing treatment for breast cancer.

Trained data collectors collected data for subjects from all three studies in the home environment. Visit length was approximately one hour. This length of time has not been found to cause undue participant burden or fatigue. In the rare instance where subjects became tired, a second home visit was made by these data collector to complete study materials. Cross-sectional data from the final (T3) measurement point of these three studies were used to test the proposed model.

Recruitment and Procedures

After human subjects (Institutional Review Board, IRB) approval was obtained for this study, data were analyzed from the final data collection time point (T3) for all subjects in the proposed current sample, which was composed of women from the control groups of studies 1, 2, and 3. An amendment granted by the UNC School of Medicine IRB allowed the expansion of communication measures at the final data collection time point for all enrolled subjects from the three studies, including current and previous intervention subjects, although only data from subjects enrolled in the control groups of these studies were used for the proposed secondary analysis. Women completed the original data collection booklet and two additional communication instruments at the final data collection time point.

To re-initiate contact with women in North Carolina from the earlier studies, women were sent an introductory letter asking if they were interested in participation in a planned follow-up of the earlier study consisting of one more data collection visit. This procedure verified contact information and allowed those who declined to participate to inform us of their preference. If a woman did not respond, contact information was verified, and the letter was re-sent. If a woman indicated via this letter that she did not wish to participate, no further contact was initiated.

Women who responded to the letter with interest, or who did not return any response, were contacted by trained recruiters who telephoned subjects and explained the nature of their requested participation (one more data collection home visit), then established eligibility, age 50 or older, and the ability to pass the mini-mental status exam (Folstein et al., 1975).

Inclusion Criteria

For the proposed secondary analysis, 130 Caucasian and 73 African American eligible women, (total N= 203) were identified as eligible and constituted the analyzed sample. Inclusion criteria consisted of being able to pass the mini-mental status exam (Folstein et al., 1975), age 50 or older, 5-9 years post original treatment, residing within North Carolina, access to a telephone, speak English fluently, and be originally enrolled in the control groups of Study 1, 2, or 3. The identified sample for the proposed secondary analysis consisted of 9 women from Study 3, 46 women from Study 2, and 148 women from Study 1.

Variable Definitions and Measures

Guided by Mishel's theory of uncertainty in illness (previously presented in Figure 2.1), a conceptual model was developed using the concepts of stimuli frame, structure providers, uncertainty, and emotional well-being (Figure 1.1). For ease in interpretation, measures of these concepts, their operational definition, and measures, are shown in Figure 3.1, and summarized in Table 3.1.

Figure 3.1 Operationalized Model of Uncertainty and Emotional Well-Being in Older Breast Cancer Survivors

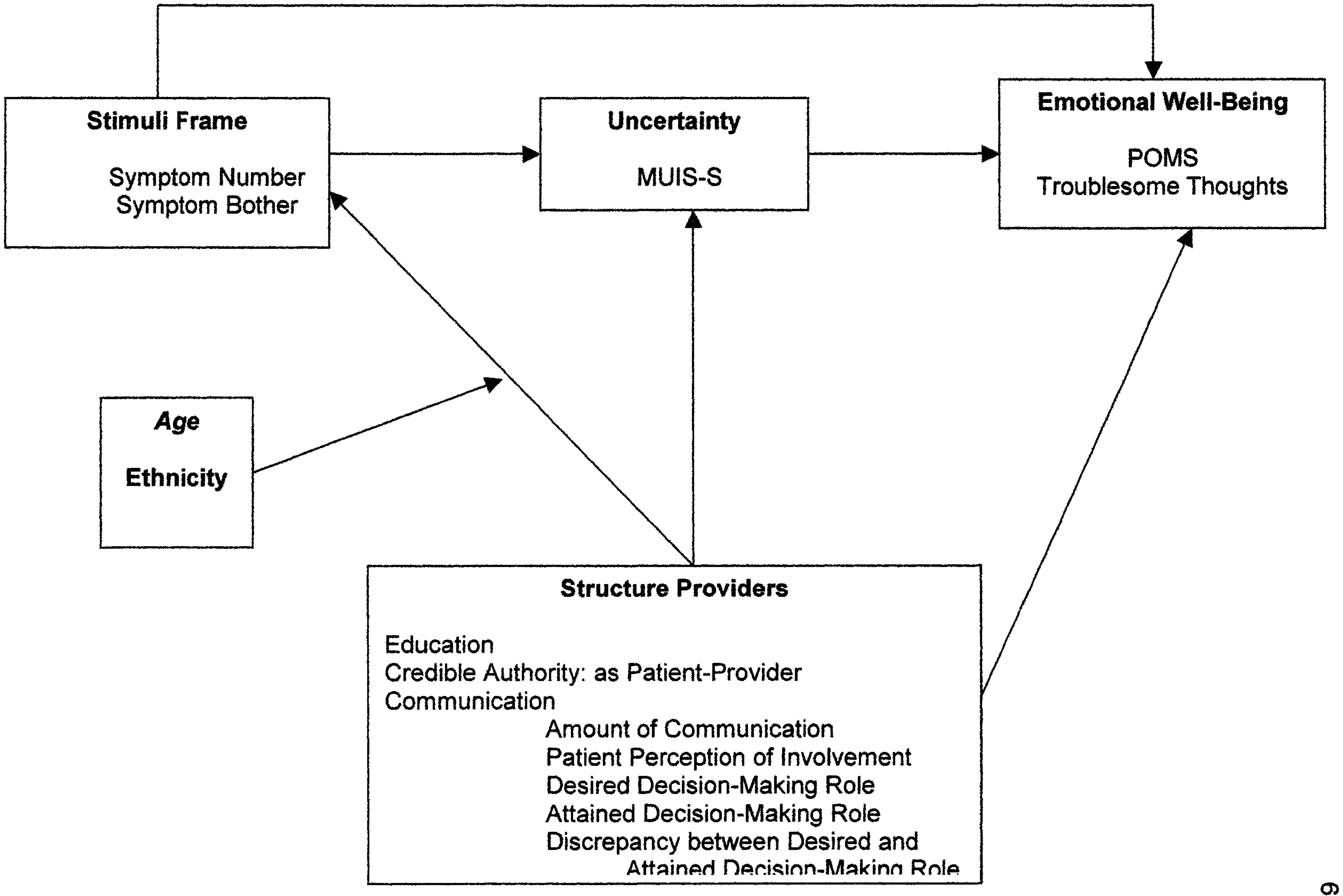


Table 3.1. Concept, Variable, and Measures.

Concept	Operalization	Measure
	Variables: Independent	
Stimuli Frame Symptom Pattern	Symptom Number Symptom Bother	Symptom Intensity Scale- Breast Cancer Survivors, A modified version of the Symptom Distress Scale McCorkle & Young, 1978
Uncertainty	Uncertainty	Mishel Uncertainty in Illness Scale- Survivor version Mishel, 1997
Structure Providers		
Patient Education	Education	Years of school
Credible Authority	Amount of Communication Patient- Provider Communication Scale	(Mishel et al., 2002b)
Credible Authority	Perception of Involvement	Patients' Perceived Involvement in Care Scale (Lerman et al., 1990)
Credible Authority	Desired decision-making role	Control Preferences Scale (Degner, Sloan, & Venkatesh, 1997)
Credible Authority	Discrepancy between desired and attained decision-making role	Control Preferences Scale (Degner et al., 1997)
	Variables: Dependent	
Emotional Well-Being	Mood State	Profile of Mood States - Short form Curan, Andrykowski & Studts, 1995
	Troublesome Thoughts	Modified version of the Negative Thoughts Inventory Gil et al. 1996
Variables: Moderating		
Ethnicity	Self identified as Caucasian or African-American	Self report
Age	Years of age	Self report

Instruments are provided as appendices (Appendices B-J). Reliability has been determined for all instruments used during the final data collection time point (combining women from studies 1,2, and 3, for analysis purposes) with the exception of the additional communication instruments. Reliability was determined for all measures used in this study as well as descriptive statistics including distributions, for each measure. The moderating effects of age and ethnicity were tested by the creation of interaction terms reflecting the product of age and all exogenous variables, as well as the product of ethnicity and all exogenous variables.

Stimuli Frame Variables

Symptom pattern, one component of the stimuli frame, was measured in this study. This concept has been operationalized to reflect the number of symptoms, and the amount of bother that women experience due to these symptoms. This variable was measured by a modified version of the 15 item Symptom Distress Scale, (McCorkle & Young, 1978). The Symptom Distress Scale was originally incorporated as a subscale of The Symptom Scale of the Southwest Oncology Group Quality of Life questionnaire (Maxwell & Delaney, 2000; Moinpour, Hayden, Thompson, Feigl, & Metch, 1990). If subjects indicate they had identified symptom, such as pain, fatigue, arm weakness, or stiffness in the arm or shoulder, they then ranked the amount of bother they attributed to that symptom from 1 (slight) to 4 (very severe). The internal reliability (Cronbach's alpha), computed using baseline data from Study 1, was 0.89. For this study, as in Study 1, the total number of reported symptoms was obtained. A total bother score for each woman was obtained with higher scores indicating a greater degree of reported bother from her reported symptoms.

The Symptom Distress Scale has demonstrated construct and convergent validity in cancer patients as shown by its high positive correlation with the Profile of

Mood States (POMS) (McCorkle & Quint-Benoliel, 1983). Additionally, in the current survivor intervention study, the subscale of symptom bother was significantly and positively correlated with the POMS total score at T1 for the total sample (.39 p=.01). Validity for the Symptom Distress Scale is found in an adapted version of the symptom distress scale (adding the symptom of vomiting, and distinguishing between occurrence and distress), demonstrated by the use of a contrasted group approach among well persons, medical surgical patients, and oncology patients, demonstrating significant differences in symptom distress between groups (Rhodes, McDaniel, Homan, Johnson, & Madsen, 2000). Similarly, Cimprich and Ronis (2001) found that 48 newly diagnosed, older (55-79 years) women with breast cancer experienced more symptom distress than 47 age matched women without breast cancer. Further, Morasso et al (1999) demonstrated a significant positive correlation (.46) between the SDS and the psychological distress inventory among 94 cancer patients of varying diagnoses.

Uncertainty

An adapted version of Mishel's Uncertainty in Illness scale (MUIS) (Mishel, 1981), was used to evaluate the level of uncertainty of breast cancer survivors. Items on the original MUIS address four identified factors of ambiguity, complexity, lack of information, and unpredictability, as described in the dimensions of the original theory, and can be summed for an overall score. The MUIS-S (survivor version) reflects the uncertainty associated with the future such as "I don't know if my cancer will ever come back," and long-term side effects, rather than treatment and diagnosis. For example, rather than "the purpose of each treatment is clear to me", this item has been modified to read, "the long-term effect of my treatment is clear to me." Responses for the MUIS-

S range from strongly agree to strongly disagree on a 5 item likert format for this 22 item scale. Higher scores reflect greater levels of uncertainty.

Various forms of the MUIS (primarily the MUIS-A, the original adult version and the MUIS-C, community version) have been used with breast cancer survivors with reliabilites (Cronbach's alpha) reported at or above .82 for the total scale (Mishel, 1984; Moinpour et al., 1990; Sammarco, 2001b; Wonghongkul et al., 2000) demonstrating good reliability in these studies. Baseline reliabilities for the MUIS-S in Study 1 are 0.82 overall, with 0.84 for Caucasian women and 0.78 for African-American women.

Construct validity for the MUIS was originally established using medical and surgical patients, and patients in the diagnostic phase of illness (Mishel, 1981). This contrasted groups approach was able to distinguish differences in uncertainty between these samples. Similarly, work by Hilton (Hilton, 1994) found that uncertainty levels were different between those breast cancer patients who had, and had not experienced recurrence. The theorized positive association between uncertainty and psychological distress is consistent, finding that uncertainty is positively associated with distress in samples of varying diagnoses including cardiac patients (Hawthorne & Hixon, 1994; Christman et al., 1988; Bennett, 1993), and breast cancer patients (Hilton, 1994; Northouse et al., 1995). Additionally, convergent validity is supported by obtained correlations using baseline data from Study 1, demonstrating a positive association between the POMS and the MUIS-S of .294.

Structure Provider Variables

Education.

In Mishel's original Uncertainty in Illness Theory, education is a structure provider variable that has a theoretically proposed direct and indirect influence on uncertainty. Indirectly education assists patients to provide meaning to the stimuli frame by helping them to structure events. Directly, patients with more education experience have been found to experience less uncertainty (Mast, 1998b). Education is self reported, measured by the number of reported years of school.

Credible authority.

The concept of credible authority, referring to the confidence and trust patients have in their healthcare providers, is operationalized as patient-provider communication. Communication is operationalized as a) the perceived amount of communication between a woman and her providers including physicians and nurses, b) the patient's decision-making role both desired and achieved, c) the discrepancy between her desired and achieved decision-making role, and d) her perception of involvement in medical decision-making. This focus was chosen because of the recognized importance of the patient-provider relationship as a direct means of reducing uncertainty (Mishel & Braden, 1988), and the known relationship between information sharing and uncertainty (Brashers et al., 2000b; Galloway & Graydon, 1996; Small & Graydon, 1993; Santacroce, 2000). Additionally, this focus was chosen in an attempt to test the current assumption in the literature that increased participation in decision-making is desired by all patients.

The Patient-Provider Communication scale, (Mishel et al., 2002b), is a five-item Likert format scale measuring how much the physician and nurse tell the patient, how much the patient tells the physician and nurse, and the amount of patient participation in planning her care. Communication between patient and provider was measured with a Likert type format ranging from 1) Nothing at all, to 5) A great deal. Higher scores indicate a greater amount of overall communication and planning with providers. A previously conducted factor analysis resulted in a single factor with eigenvalue greater than one, with all items loading at or above 0.50 (Mishel et al., 2002b), therefore scores were summed to reflect an overall communication score. Previous work with this scale has demonstrated a reliability of .75 in men with prostate cancer (Mishel et al., 2002b). Reliability of the scale in the larger survivor intervention study is 0.76 overall, with 0.76 for Caucasian women and 0.78 for African-American women.

Validity was assessed as part of the findings from this study. Previous use of this tool among prostate cancer patients did not show the expected increase in the amount of patient-provider communication as an outcome resulting from an intervention designed to assist men to manage uncertainty (Mishel et al., 2002b; Mishel et al., 2001). However, men did report that patient-provider communication was a continual problem for them, suggesting that this tool possesses content validity. In this study it was expected that this scale would be positively correlated with the Patient's Perceived involvement in Care scale (Lerman et al., 1990). The three subscales of the PICS address items very similar to those contained in the Patient-Provider Communication scale. The doctor facilitation subscale of the PICS addresses what the provider asked the patient, and the patient information subscale addresses what the patient asked the provider. The final subscale of the PICS, patient decision-making, addresses the perceived input a patient has during the decision-making process. It is hypothesized that patients who perceive themselves to have a higher degree of involvement in the patient-provider relationship will also report greater overall amounts of communication with providers.

<u>The Patient's Perceived Involvement in Care Scale</u> was used to assess a woman's perception of her involvement in decision-making (Lerman et al., 1990). The PICS was designed to address the exchange of information and the amount of control between physicians and patients. The scale was initially developed with 3 samples of adult primary care patients who were seeking treatment for new symptoms or

exacerbations of existing symptoms. As predicted, patient's perceptions of providers' efforts to encourage their participation was found to be positively correlated with increased self reported understanding of their illness (Lerman et al., 1990). Exploratory factor analysis identified 3 subscales: physician facilitation of patient involvement (5 statements), level of information exchange (4 statements), and patient participation in decision-making (4 statements). Alpha coefficient for the initial sample of 131 patients demonstrated a reliability of .73. Reliabilities were assessed and factor analysis performed. Results are reported in Chapter 4. Responses to the 13 statements are dichotomous, and were dummy coded with 1 representing agreement and 0 representing disagreement.

Items were originally developed from observations of primary care visits. Face and content validity was established with these patients and 8 primary care providers. Beginning construct validity was shown by demonstrating the association in the predicted direction that more involved patients would be more satisfied with their care as measured with the Ware satisfaction Scale (Lerman et al., 1990; Ware, Snyder, & Wright, 1976). Further support was found for the PICS showing that increased involvement was positively associated with increased understanding, reassurance, control, and improvement in functional capacity in adult ambulatory care patients of mixed diagnoses (Lerman et al., 1990).

The Control Preferences Scale was used to assess a woman's preference for involvement in medical decision-making (Degner et al., 1997). Control is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment" (Degner et al., 1997) (page24-25). This instrument has been widely used in a variety of populations including breast cancer patients, and has been found to be an easily administered measure of a patient's preferred role in healthcare decision-making (Degner et al., 1997; Degner et al., 1997b). Subjects are presented with a series of paired cartoons representing 5 different roles ranging from active, through collaborative, to passive roles in medical decision making until each role has been compared with the total set of 5 different role options. Responses are selected as the preferred option for each pair until all combinations have been presented. The result is the patient's ordered preference of the 5 roles from most preferred to least preferred decision-making role. Roles are selected in the context of the disease process under investigation. In this study women were asked to select their preferred role in the context of their last visit to their provider for symptoms they knew, or were fearful of, being related to their breast cancer. Data collectors were trained to present this tool within the context of symptoms related to breast cancer.

The Control Preferences Scale is based upon Coomb's unfolding theory, which hypothesizes that an individual's preference can be found as a distinct point on a continuum (Degner et al., 1997). This point can be discovered for an individual by presenting successive paired comparisons to subjects. There are 11 valid ordered role sequences for the Control Preference Scale, ranging from a sequence reflecting the most active role preference sequence ABCDE to the most passive role preference EDCBA. Coomb's theory states that if 50 plus 1 subjects preference orders fall on the metric (for a 5 point metric, such as for the CPS, there are only 11 valid ordinal responses) the scale is reliable. Additionally there must be a reversal (EDCBA) of the original metric (ABCDE) in these data set. Previous large studies in cancer populations (N= 400-1000) have found approximately 58-66% of responses fall within the 11 valid sequences (Beaver et al., 1996; Degner et al., 1997b; Degner & Sloan, 1992). Yet even when invalid sequences are chosen, the first and second preferences chosen have found to be valid and can be used for analysis of a subject's preferred decision-making role (Degner et al., 1997). Ordinal scores can be assigned to each of the identified valid sequences, or data can be collapsed into 3 categories reflecting active, collaborative, or passive preferences and assigned ordinal scores. Analysis of subjects preferred decision-making role as predicted by other variables is usually performed using regression. Responses can be coded in a range from 1-5 with 1 representing the most active decision-making role and 5 representing the most passive decision-making role. Additionally cross tab and chi square analysis can be utilized to discover if there are differences between the most preferred decision-making roles (Degner et al., 1997). Further, decision-making roles can be collapsed into active, collaborative, and passive categories, then assessed for their relationship to other variables such as age or ethnicity using chi-square or ANOVA (Beaver et al., 1996).

This study also assessed the single role (from the 5 presented options) that subjects felt most closely resembled what actually happened during decision-making with her provider. The discrepancy between a woman's most preferred and actual adopted role was assessed by calculating a difference score between preferred and attained role. For example, the discrepancy score was –2 for a woman who's most preferred role is collaborative (a 3, using 1 for most active and 5 for most passive), yet who reports that the role she actually adopted with her provider was totally passive (a 5 using the 1-5 rating). This discrepancy score indicates both the magnitude and the direction of the discrepancy between her preferred and adopted role.

Reliability of the CPS has been demonstrated in cancer populations by consistently meeting Comb's requirement of 50% plus one subjects who fall on the metric dimension of ABCDE out of 60 other possible dimensions, and the existence of a score reversal in these data set (Degner et al., 1997). Should data fail to meet these criteria, the scale cannot be considered reliable within the studied sample, per Coombs unfolding theory (Degner et al., 1997).

The CPS was originally developed from qualitative work describing the context of decision-making, finding that decisions were made within a social context rather than as a sole function of diagnosis or available treatment (Degner et al., 1997). This early qualitative work led to observations that patients had distinct preferences for control in decision-making. A distinction was made during the development of the CPS between the desire for information and the desire for decision-making control, concepts that had previously been indistinct from each other (Degner et al., 1997). Cartoons as well as statements were included to ensure the instrument could be used with populations of varying literacy levels. Original pilot testing of the CPS was conducted among men with testicular cancer, finding that statements were understandable and that men understood the concept of decisional choice within a continuum from passive to active involvement, establishing face validity (Degner et al., 1997).

The CPS is able to discriminate between decisional preferences among patients with multiple types of diagnoses. Construct validity is shown through continued findings showing that patients with a wide variety of diagnoses (including parents of ill children) have systematic preferences regarding the desired level of decision-making involvement and are able to discriminate between the 5 portrayed roles (Beaver et al., 1996; Pyke-Grimm, Degner, Small, & Mueller, 1999; Ramfelt, Langius, Bjorvell, & Nordstrom, 2000; Stewart et al., 2000). Further support for the CPS's ability to demonstrate a patient's understanding of a continuum of decisional preference is found by the ability to discriminate between actual and preferred decisional roles in a large study of breast cancer survivors (Degner et al., 1997) as well as in a sample of colorectal cancer patients (Ramfelt et al., 2000). However, this tool has been predominantly used in Caucasian subjects with cancer. An important contribution of this study was the use of this instrument with African American participants (personal communication Dr. L. Degner, 1/30/02).

Emotional Well-Being

The dependent variables of mood state and troublesome thoughts were chosen to operationalize emotional well-being. Measures selected were the Profile of Mood States-Short Form (POMS-SF) (Curran, Andrykowski, & Studts, 1995), and a modified version of the Negative Thoughts Inventory (Gil et al., 1996).

The Profile of Mood State- Short Form (POMS-SF) measures mood state, consisting of 37 one word statements such as energetic and hopeless. Respondents were asked to respond to each mood state, selecting from 5 items ranging from not at all to extremely. Higher scores indicated greater levels of mood disturbance. This tool has been extensively used in many populations including cancer populations (Mishel & Sorenson, 1991). Among older newly diagnosed breast cancer patients reliability has been reported to be .86-.93 over three time points (Cimprich & Ronis, 2001). Validity in breast cancer survivors up to 3 years post treatment is demonstrated by a consistent inverse relationship over three time points with the CARES including the psychosocial subscale (lower scores on CARES indicate less problems and improved quality of life) (Ganz et al., 1996). In the survivor intervention study the POMS has demonstrated significant correlations with troublesome thoughts, supporting it's use along with troublesome thoughts as an indicator of emotional well-being in this sample. Reliability for the POMS-SF in the Study 1 is 0.95 overall, with 0.95 for Caucasian women and 0.95 for African-American women for the POMS-SF.

The modified Negative Thoughts Inventory (Gil et al., 1996) assesses a woman's troublesome thoughts regarding breast cancer recurrence that may be triggered by conversations with other breast cancer patients, interactions with providers, or physical symptoms and is subsequently referred to as the Inventory of Troublesome Thoughts. This 15 item scale asks respondents to select among 5 options from Never (1) to Always (5) presented in a 5 option Likert type format. This scale addresses thoughts such as "The doctor might be wrong," and "This pain could only mean cancer." Higher scores indicate a higher level of troublesome thoughts. The Negative Thoughts Inventory (Gil et al., 1996) was originally developed with sickle cell patients. Preliminary analysis with breast cancer survivors from Study 1 has shown the expected positive correlation (.38) with the POMS, demonstrating content and convergent validity in this sample. Preliminary reliability for the Inventory of Troublesome Thoughts using baseline data from women enrolled in Study 1 is 0.87 overall, 0.86 for Caucasian women and 0.90 for African-American women in the larger intervention study.

Analysis

Sample

The sample was described using measures of central tendency to assess the distribution of scores on the continuous variables of Symptom Distress, Symptom number, Uncertainty, Age, Education, total amount of communication, POMS, and the Inventory of Troublesome Thoughts. The means, standard deviations, and range were calculated. For variables that were not normally distributed, kurtosis and skewness assessed and variables were visually assessed using data plots. The continuous variable of preferred decision-making role preference was described using Coombs unfolding theory, as well as described using measures of central tendencies, frequencies and percentages. The dichotomous variables of Ethnicity and Perception of Involvement in Care were described using frequencies and percentages. Nominal variables of attained decision-making role preference and the discrepancy between preferred and attained roles were also described using frequencies and percentages.

Psychometrics

To assess internal consistency, reliabilities were performed for all instruments on the total sample as well as by ethnicity using Cronbach's alpha. Additionally confirmatory factor analyses was used to determine whether the factor structure of the Patient Perception of Involvement in Care scale was similar in this sample of cancer survivors to the factors originally obtained with adult ambulatory care patients. Convergent validity was confirmed by the positive correlation between the Patient-Provider Communication scale and the PICS as anticipated.

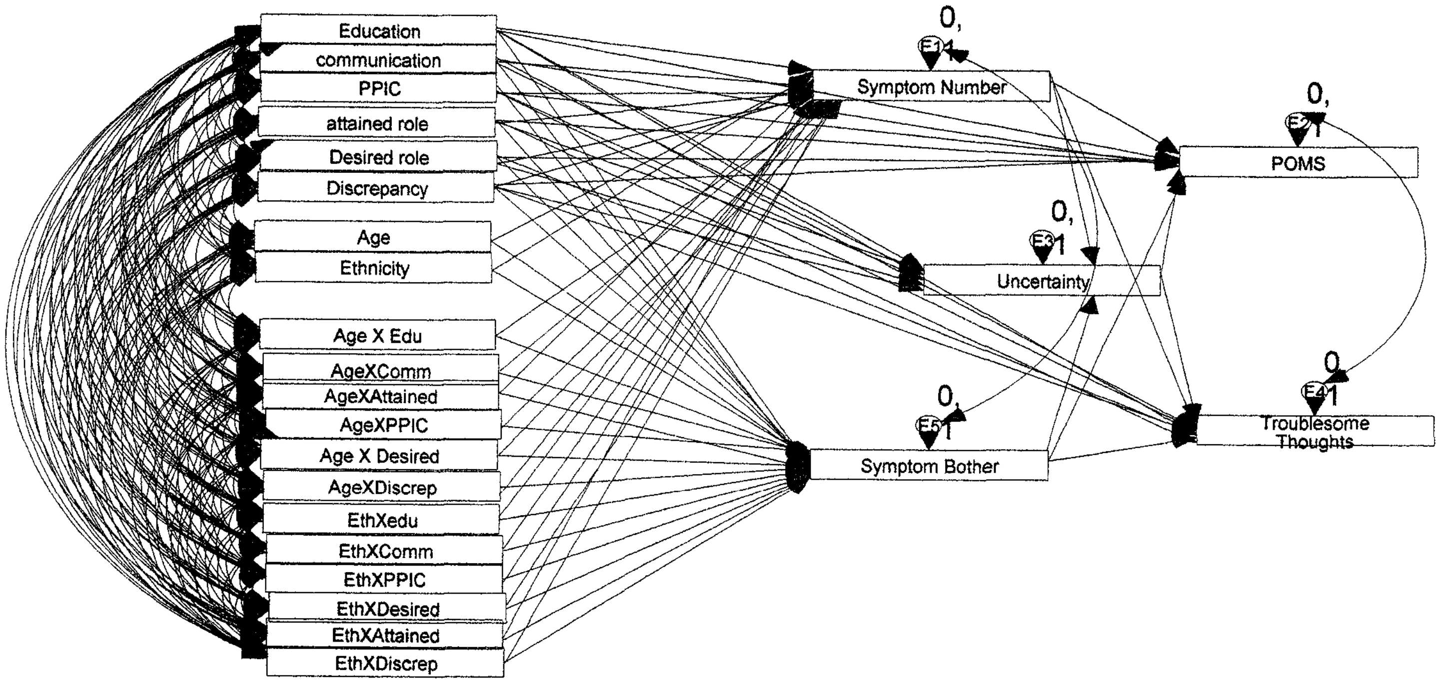
Chi square analysis was used to indicate whether there was a significant difference between a woman's actual vs. preferred role preference. The direction of discrepancy was also assessed. In a large (N= 1,012) study of newly diagnosed breast cancer patients only 42% felt they had attained their desired role preference, and further, while 15% felt they had adopted a more active decision-making role that they desired, the majority of previously diagnosed women felt that they had achieved less control than they desired in the decision-making process (Degner et al., 1997b; Luker, Beaver, Leinster, & Owens, 1996).

Model development

Structural Equation Modeling, SEM, was used to test the proposed causal linkages between variables. It is important to use theory to guide the selection and ordering of variables in SEM due to the need for imposing an hypothesized linear (recursive) order on selected variables (Norris, 2001a; Pedhazer & Schmelkin, 1991; Pedhazer, 1997). The proposed path model (Figure 3.2) was developed using

Uncertainty in Illness Theory, which provided the theoretical rationale for the proposed relationships between selected variables (Mishel, 1988).

Figure 3.2 Path Model of Emotional Well Being in Older Breast Cancer



Power

Power for the proposed structural equation model was calculated using an alpha level of .05, effect size of .80, with a sample size of 203 and RMSEA (root mean square error of approximation) goodness of fit test, set at .05-.08 based on null and alternative values (MacCallum, Browne, & Sugawara, 1996). The result was .714 and was sufficient to detect differences between groups. If the alternative hypothesis value is relaxed to .09, power is increased to .912. Hoyle and Panter (1995) note that the power of a model is a function of sample size as well as the characteristics of the model, and further that there are no established and agreed upon cut-off limits for goodness of fit indices. These authors consider low power to be less than .60.

For the proposed model of emotional well -being in breast cancer survivors, the number of observed (manifest) variables is 25 (symptom number and bother, uncertainty, education, amount of communication, perception of involvement, desired and attained role, and the discrepancy between these roles, mood state, troublesome thoughts of recurrence, age, ethnicity, and interaction terms). There are 5 error terms. The number of known values, or co-variances, was estimated using $n(n+1)/2$ where n was the number of variables in the model (Bollen, 1989). 308 parameters (including error estimates) were estimated. Degrees of freedom (350-308=42) is positive, allowing the rejection of the model to be tested. Standardized path coefficients were reported to facilitate comparison among variables.

Model Analysis

Only manifest (observed) variables were selected due to the reduced measurement error associated with manifest versus latent variables. The error portrayed in the model reflects error in the equation rather than error in measurement (perfect measurement is an assumption required by SEM). This approach was chosen due to the complexity of analyzing interaction terms in models incorporating latent variables. The result is ease of interpretation of interactions, increased power due to the fact that fewer parameters are estimated, and an ability to use smaller sample sizes rather than the very large samples usually needed for SEM using latent variables.

Analysis using structural equation modeling techniques requires the same assumptions as regression models. These assumptions are: 1) normally distributed and continuous variables (although newer statistical programs such as M-plus have been developed allowing the use of dichotomous variables), 2) homoscedasticity, or the need for every value of X to have a distribution of Y scores with equal variability for each independent variable, 3) that residuals are not correlated and that all relevant variables have been included in the model, and 4) that variables are measured without error (Norris, 2001a; Pedhazer & Schmelkin, 1991; Pedhazer, 1997). A residual analysis was performed to check if these data meet these assumptions. An additional requirement of SEM is that there is a linear (recursive) relationship between variables (Norris, 2001a).

Advantages of SEM over regression are that SEM provides more information than regression by decomposing the relationship between variables into both direct and indirect effects, and further SEM allows more than one dependent variable. Additionally, SEM provides an estimate of the goodness of fit of the model to these data. In this study, both direct and indirect effects on uncertainty and emotional well-being were assessed.

In SEM, conclusions can only be considered valid if the fit of these data to the measurement model is adequate (Norris, 2001b). Results are expressed in terms of path coefficients, and computed using maximum likelihood estimation (Hoyle & Panter, 1995). Other terms used synonymously with path coefficients are parameters or parameter estimates (Norris, 2001b). These parameters are either fixed or free. When the researcher assigns a value to a parameter it is considered fixed. SEM produces both a parameter estimate, as well as a test of significance for each path analyzed.

Goodness of fit indices assess model fit. Currently, researchers and statisticians do not agree on what constitutes acceptable cut off points for goodness of fit, however, .90 is arbitrarily used for most indices, and considered acceptable (Hoyle & Panter, 1995). Similarly, there is no agreement on what constitutes the best goodness of fit index, therefore it is commonplace to include multiple indicators (Hoyle & Panter, 1995). Hoyle and Panter (1995) recommend chi-square as a stand alone fit index, accompanied by the corresponding sample size, *df* and *p* values. Other recommended indices are the Tucker-Lewis index, although this index is not recommended for samples of less than 150 subjects. When smaller samples are used, the Incremental fit index is recommended as it is less variable the Tucker-Lewis index in smaller samples (Hoyle & Panter, 1995). Recently the RMSEA (root mean square error of approximation) has been recognized as one of the most informative fit indices (Byrne, 2001). This index is sensitive to the complexity of the model and reflects the number of estimated parameters using available degrees of freedom. Values below .05 are indicative of good model fit, and values of .05 to .08 are considered acceptable fit (Byrne, 2001). RMSEA takes into account the error of approximation in the model and assesses how well the model would fit the population should that covariance matrix be available (Byrne, 2001). When presenting goodness of fit indices, Hoyle and Panter (1995) stress that it is not necessary to present all fit indices contained in the output from statistical software packages. Rather, the researcher should select appropriate goodness of fit indices based up the sample size and specific models tested (Hoyle & Panter, 1995).

Often post-hoc model specification is applied to improve the fit of the model to these data. Selected parameters are deleted based upon theoretical rationale. Additionally, researchers may choose to retain paths that are considered theoretically important despite nonsignificance (Hoyle & Panter, 1995). It is important that the final discussion includes a description of how the final model was derived from the originally presented theoretical model (Hoyle & Panter, 1995). Comparison of goodness of fit between models is best accomplished with stand alone indices such as the chi-square rather than other types of fit indices (Hoyle & Panter, 1995). The proposed structural equation model was specified post-hoc using the critical ratio 1.96 as the criteria for retaining paths between variables.

Data Analysis Software

Data were entered using SPSS software. Analyses were performed using Analysis Of Moment Software, AMOS, (Chicago, IL).

Summary

This study tested a conceptual model of uncertainty and emotional well-being among older African American and Caucasian breast cancer survivors. The model was tested using structural equation modeling rather than regression to allow estimation of direct as well as indirect effects. The use of observed variables rather than latent variables facilitated ease of interpretation and analysis of the interaction terms and reduced the need for large sample sizes to achieve adequate power. The model to be tested was theoretically developed, a strongly suggested pre-requisite of when using structural equation modeling techniques, from Uncertainty in Illness Theory (Mishel, 1988). The instruments chosen possess validity and good reliability in cancer populations.

Additionally, the Control Preferences Scale has not been used in a sample of African-American women, therefore the use of this instrument contributed to the validity of this instrument for different ethnicities (personal communication Dr. Leslie Degner, 1/30/02). Finally, this model tested the entire theoretical model of uncertainty in illness. Previous research has only focused on specific parts of the model (personal communication, Dr. Merle Mishel, 1/25/03).

CHAPTER FOUR: RESULTS

Introduction

To address the research questions, structural equation modeling was used to assess the influence of symptom number and bother, uncertainty, and patient-provider communication on the emotional well-being of older breast cancer survivors. After a summary of the major research questions, sample characteristics are described and reliabilities are reported. The initial test of the model of emotional well-being in older breast cancer survivors is presented, as is a reduced alternative model. Both direct and indirect paths (testing the mediating influence of uncertainty) to emotional well-being were tested, as well as the moderating influence of age and ethnicity on the relationship between patient-provider communication and symptom number and bother. Finally, measures to assure the accuracy of these data and to ensure these data conform to the necessary assumptions of regression are presented. Analysis was completed using SPSS 11.0, (Chicago, IL) and Analysis of Moment Software (AMOS) (Chicago, IL).

Sample

Demographic data are summarized in Tables 4.1 and 4.2. Two hundred and three Caucasian and African-American breast cancer survivors were identified as eligible for this secondary data analysis. Subjects were obtained from three previous studies as described in Chapter 3. All were age 50 or older, free from recurrence, 5-9 years from original diagnosis and treatment, could speak English, and had access to a phone. Additionally, all scored 27 or higher on the Mini-Mental exam, indicating an ability to comprehend instructions and answer research questionnaires (Folstein et al., 1975). The sample was composed of 130 Caucasian women (64%) and 73 (36%) African-American women (N = 203) (Table 4.1). Mean age for the total sample was 63.3 years (SD = 9.6). Mean educational level was 13.3 years (SD = 3.03). Most women were not working, although 20% were working full time. A graphic inspection of these data showed that it was the comparatively younger women who were employed part or full time. By age 80 less than 5% of women were employed outside the home (Figure 4.1). Additionally, 53% of the women were married, although again the percentage of married women decreased with age (Figure 4.2). Marital data were unavailable for 9 women and employment data were unavailable for 18 women.

Women were asked to identify the provider that they consulted for their current breast cancer symptoms and concerns. This was not necessarily the provider that had provided initial treatment 5 or more years, ago, but rather the provider with whom they currently discuss their breast cancer concerns. Most saw an oncologist for symptoms they thought might be related to breast cancer, but many sought care from their family doctor and a small percentage sought care from providers such as nurse practitioners. Other types of providers consulted by women included gynecologists, surgeons, cardiologists, and chiropractors.

To assess if there were differences between subjects obtained from the three different studies, means and standard deviations were examined (Table 4.3). Additionally, an ANOVA was performed by original subject group for all variables (Table 4.4). Groups differed by age, attained role, amount of patient-provider communication, and ethnicity. There was no difference between groups on any other variables.

Post hoc analysis (Tukey's pairwise) of these differences found all groups differed by age and ethnicity, however, given the original inclusion criteria this was expected. Women obtained from "Promoting self-help: Underserved women with breast cancer" (R01 CA 64706-02, PI: C. Braden) (N=9) were all African American, and additionally were younger than the other two groups. There was no significant difference by age between the other two groups, "Managing uncertainty: Self help in breast cancer" (R01 CA 57764-04) PI: M. Mishel (N=46), and "Managing uncertainty in older breast cancer survivors" (RO1 CA 78955 03) PI: M. Mishel, (N= 148). However, when groups were combined, inclusion criteria were met, in that all women were either African American or Caucasian, age 50 or older and 5-9 years post treatment.

The other two significant differences between study groups involved communication variables. Women obtained from "Promoting self-help: Underserved women with breast cancer" (R01 CA 64706-02), (N=9) had more total patient-provider communication than women obtained from "Managing uncertainty: Self help in breast cancer" (R01 CA 57764-04), (N=46). No other significant differences were found in total communication between the three groups. Regarding the differences in attained decision-making role, the only difference between groups was between women from "Managing uncertainty: Self help in breast cancer" (R01 CA 57764-04) (N=46), and "Managing uncertainty in older breast cancer survivors" (RO1 CA 78955 03), (N= 148).

Reasons for these communication differences are not well understood, but it may be that the reason for the differences in total patient-provider communication between subject groups are related to age, in that the 9 younger women received more overall communication. This finding is consistent with a known age bias reflecting a lack of communication between providers and older patients that is reported frequently in the communication literature (Comstock, Hooper, Goodwin, & Goodwin, 1982; Greene, Adelman, Charon, & Hoffman, 1986). Similarly, there is recognized ethnic bias in the way providers treat African American patients as opposed to Caucasian patients, possibly affecting their ability to attain their desired decision-making role (Roter, Hall, & Katz, 1988); (Starr, 1982). This ethnic bias may partly explain the differences in attained decision-making role between the two larger groups of women in that there was a higher percentage of Caucasian women (72%) obtained from “Managing uncertainty in older breast cancer survivors” (RO1 CA 78955 03) (N=148), as opposed to the percentage of Caucasian women (50%) obtained from “Managing uncertainty: Self help in breast cancer” (R01 CA 57764-04) (N=46). Additionally, there simply may not have been enough variation in the smaller African American group to detect differences between these women and the two other larger groups.

In summary, although some differences were found between women obtained from the three different studies, it is felt that these differences were either expected, or related to expected differences, in age and ethnicity. Since this study is designed to allow variation in age and ethnicity, it is felt that women from the three studies can be analyzed as a single group representing Caucasian and African American breast cancer survivors over age 50, who are 5-9 years from original treatment.

Table 4.1. Mean, Standard Deviation, and percentage of sample demographic characteristics.

	Mean	SD	(Percentage)	Frequency
Age in years (N=203)	63.33	9.6		
Years of school completed (N=203)	13.31	3.03		
Ethnicity (N=203)				
African American			(36)	73
Caucasian			(64)	130
Type of Provider Consulted for Breast Cancer Symptoms (N=203)				
Oncologist			(52)	107
General Family Doctor			(35)	72
Other			(10)	21
Nurse Practitioner			(1.5)	3

Table 4.2 Employment and Marital status percentage, and frequency.

	Percent	Valid Percent	Frequency
Employment status (N=185)			
Other	3.45	3.78	7
Medical Leave from part time job	0.49	0.54	1
Medical Leave from full time job	3.94	4.42	8
Retired not working	36.95	40.54	75
Retired working part time	12.81	14.05	26
Homemaker	5.42	5.95	11
Unemployed	1.97	2.16	4
Working full time	20.69	22.70	42
Working part time	5.42	5.95	11
Total	91.13	100.00	185
Marital status (N= 194)			
Married	53.20	55.67	108
Living with partner for 6+ months	0.49	0.52	1
Separated	1.48	1.55	3
Divorced	7.39	7.73	15
Widowed	28.08	29.38	57
Never married	4.103	5.15	10
Total	95.57	100.00	194

Figure 4.1 Employment status by decade

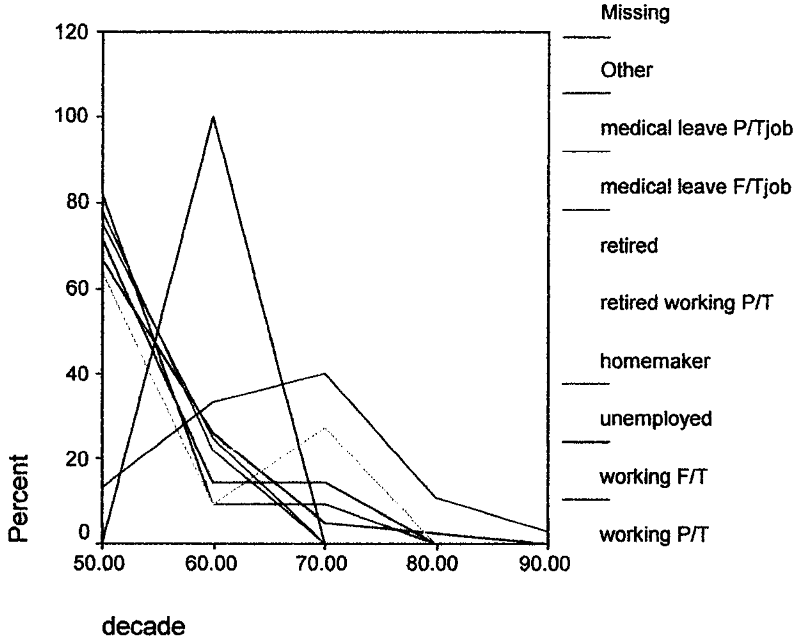


Figure 4.2 Marital status by decade

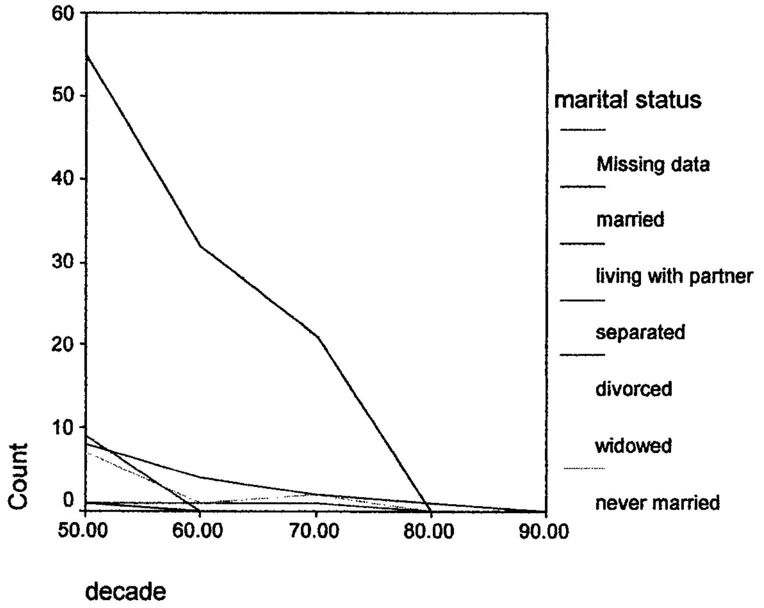


Table 4.3 Means and Standard Deviations of variables by research group.

	Managing uncertainty: Self help in breast cancer (R01 CA 57764-04) PI: M. Mishel		Promoting self-help: Underserved women with breast cancer (R01 CA 64706-02) PI: C.Braden		Managing uncertainty in older breast cancer survivors (RO1 CA 78955 03) PI: M. Mishel	
	N=46		N=9		N=148	
Measure	Mean	Std Dev.	Mean	Std Dev.	Mean	Std Dev.
Education	12.74	4.00	13.89	2.26	13.46	2.72
Age	63.09	8.38	52.33	2.06	64.08	9.85
Discrepancy	-0.09	1.11	-0.22	0.83	0.09	0.93
Desired role	3.00	0.94	2.89	0.78	2.8	0.79
Attained role	3.43	1.13	2.67	0.71	2.98	0.84
Patient Perception of Involvement in Care	6.13	3.00	8.33	1.73	6.89	3.05
Patient-provider communication	15.54	4.12	20.22	4.32	16.94	4.80
Symptom bother	0.52	0.77	0.42	0.45	0.45	0.55
Symptom Total	4.84	3.86	4.12	3.06	4.105	3.95
Uncertainty	57.09	10.35	55.42	6.90	56.5	9.74
Troublesome Thoughts of Recurrence	19.54	5.67	19.33	4.53	21.54	6.80
Profile of mood states	30.96	15.36	22.33	11.95	32.47	18.09

Table 4.4 Differences between subjects by research group.

Measure	Sum of Squares Type III	df	Mean Square	F
Education	21.31	2	10.65	1.16
Age	734.78	2	367.34	3.98*
Discrepancy between roles	1.80	2	0.90	0.96
Desired role	1.46	2	0.73	1.07
Attained role	8.79	2	4.50	5.29*
Patient Perception of Involvement in Care	42.98	2	21.49	2.39
Patient-provider communication	7.62	2	3.81	4.37*
Symptom bother	0.21	2	0.10	0.29
Symptom number	6.98	2	3.49	0.23
Uncertainty	0.01	2	0.01	0.03
Troublesome thoughts of recurrence	1.15	2	0.58	2.24
Profile of Mood States	0.66	2	0.33	1.51
Ethnicity	5.61	2	2.80	13.63*

*$p \leq 0.05$

Psychometrics

Scale reliabilities were calculated using Cronbach's Alpha. Psychometrics are reported in table 4.5 and the mean, standard deviation, and range of responses are reported in Table 4.6.

Table 4.5. Scale Reliability Coefficients (Cronbach's Alpha) (N=203)

Instrument	Total Sample	Caucasian	African American
Symptom bother	0.90	0.89	0.90
Uncertainty	0.81	0.85	0.70
Patient-provider communication Scale	0.79	0.79	0.78
Patient Perception of Involvement in Care	0.77	0.78	0.75
Doctor Facilitation Subscale	0.67	0.67	0.68
Patient Information Subscale	0.66	0.68	0.62
Decision-making Subscale	0.60	0.57	0.63
Troublesome thoughts	0.82	0.84	0.78
Mood state (POMS)	0.93	0.93	0.92

Table 4.6. Range, Mean, and Standard Deviation of scales (N=203)

	Range	Mean	SD .
Symptom bother	0 - 2.93	0.46	0.59
Uncertainty	29 - 86	56.86	9.86
Patient-provider communication scale	5 - 25.0	16.77	4.93
Patient Perception of Involvement in Care scale	0 - 13	6.78	3.02
Troublesome thoughts	13 - 46	21.54	6.64
Mood state (POMS)	0 – 101	31.67	17.3

Missing data was found for four subjects on the Uncertainty scale, (mammogram question only), and for one subject on the patient-provider communication scale. Missing data was replaced by calculating the mean for that particular item, then replacing the missing data with the mean of that item, prior to other transformations such as summing, centering, and computing total scale means and reliabilities.

There was an exceptionally small amount of missing data in this data set due to initial inspection of these data collection booklets prior to data entry. When data were missing, the booklet was returned to these data collector for verification with the subject. This inspection also detected response bias and validity of responses. For example, if a subject stated they were very tired on one scale (symptom bother) it is to be expected that they were not full of pep on another (POMS). When questions arose, data were returned to these data collector for verification by the subject. Sometimes a second data collection interview was scheduled to avoid subject fatigue. The result of this procedure is a data set that is virtually free of missing data, and accurately reflects subject responses, avoiding responses that do not reflect the subject's true state due to conditions such as fatigue.

Scale Properties

Symptom Distress Scale

Both symptom number and bother were calculated using a modified version of the Symptom Distress scale (McCorkle & Young, 1978). Symptom number was calculated as a summed count of the total number of symptoms reported by each woman. If a woman did not have a particular symptom the original data code, 9, was replaced with a zero prior to calculating the total number of symptoms for each subject. Thus, the scale was able to be summed, with zeros reflecting the absence of a particular symptom.

The number of potential symptoms was 15. Twenty-five women reporting no symptoms and 4 women reported experiencing all 15 symptoms. The majority (78%) of women reported experiencing between 0 and 7 symptoms. The most frequently reported symptoms were numbness, skin sensitivity, tender areas and fatigue (Table 4.7). Higher scores indicated a greater number of reported symptoms. The mean number of symptoms for the total sample was 4.9.

Symptom bother was calculated as a mean score representing the overall degree of bother experienced by women with symptoms. For example, if a woman indicated she had fatigue, she then responded to the question: How much does it distress or bother you? Responses ranged from not at all (0) to very much (4). The amount of bother was then summed and divided by the total number of symptoms reported. For this sample the overall average bother score was low, ranging from 0-2.93 with a mean overall bother score for the entire sample of 0.46 (SD = 0.59). Ranges, means and standard deviations are reported in Table 4.6. Larger bother scores indicate a higher level of overall reported symptom bother. Reliability (Cronbach's alpha) for the total sample was .90 for symptom bother, .89 for Caucasian women and .90 for African-American women (Table 4.5).

Table 4.7 Number of Symptoms sorted by percentage of total sample (N=203)

Symptoms	Frequency	(Percent)
numbness	127	(62.6)
sensitive skin	89	(43.8)
tender skin	88	(43.3)
fatigue	82	(40.4)
arm weakness	80	(39.4)
stiff arm	78	(38.4)
weight gain	63	(31.0)
pain	58	(28.6)
limited shoulder motion	53	(26.1)
arm swelling	48	(23.6)
hard dry skin	48	(23.6)
hand swelling	45	(22.2)
trouble thinking	44	(21.7)
appearance	29	(14.5)
change in appearance of scar	29	(12.6)

Patient perception of involvement in care

The patient perception of involvement in care scale (Lerman et al., 1990) is a 13 item dichotomous scale (agree / disagree). The range for the patient perception of involvement in care scale was 0-13 with a mean of 6.78 (SD = 3.02) (Table 4.6). Higher scores indicate more participation in decision-making and treatment planning. Items indicate whether women feel involved in their care, for example: My doctors encouraged me to talk about personal concerns related to my symptoms.

Factor analysis was performed to assess construct validity using principle axis extraction with promax rotation. Based on selecting eigenvalues greater than 1.0, 4 initial factors were extracted, however the last factor only contained two items, therefore a three factor solution was computed. Items loaded on original factors found by Lerman (1990), except for one item. In the original scale the item "I asked my doctor to explain the treatment or procedure to me in greater detail" loaded on the second factor, patient information, rather than on the first factor, doctor facilitation. The decision-making subscale factored identically to the original scale. The three factors were modestly correlated with each other at .30-.34. All factors demonstrated eigenvalues above 1.0 and loadings above .514, summarized in Table 4.8.

Reliability (Cronbach's alpha) for the total sample was 0.77 (Table 4.5). Reliability was assessed for both the total and the 3 subscales of the Patient's Perceived Involvement in Care scale: Doctor Facilitation, Patient Information, and Decision-making. None of the subscales were found to be more reliable than the scale total, therefore the total scale was used for analysis. Item range, mean and standard deviation and reliabilites are summarized in Table 4.9. This scale has not been widely used, and can be considered relatively new. Although reliabilites are lower than that of an established scale, they are above the generally accepted cut off of .70 for a new and relatively unused scale (Ferketich, 1990). These reliabilities are similar to those initially found by Lerman (1990).

Table 4.8. Factor analysis of the Patient's Perception of Involvement in Care scale.

Items	Factors		
	1	2	3
My doctor encouraged me to give my opinion about my treatment.	**.758**	.243	.328
My doctors encouraged me to talk about personal concerns related to my symptoms.	**.700**	.307	.185
My doctor asked me whether I agree with his/her decisions.	**.662**	.124	.192
My doctor asked me what I believe is causing my symptoms.	**.534**	.519	.325
I asked my doctor to explain the treatment or procedure to me in greater detail.	**.523**	.426	.348
My doctor gave me a complete explanation for my symptoms or treatment.	**.514**	.092	-.008
I asked my doctor a lot of questions about my symptoms.	.294	**.827**	.205
I detail my sym I went into great detail about my symptoms.	.089	**.791**	.201
I asked my doctor for recommendations about my symptoms.	.302	**.643**	.161
I insisted on a particular kind of test or treatment for my symptoms.	.088	.261	**.767**
I suggested a certain kind of treatment to my doctor.	.300	.178	**.753**
I gave my opinion (agreement or disagreement) about the types of test or treatment that my doctor ordered.	.498	.229	**.592**
I expressed doubts about the tests or treatment that my doctor recommended.	.105	.081	**.559**

Extraction Method: Principal Component Analysis.
Rotation Method: Promax with Kaiser Normalization.

Table 4.9 Item Means, standard deviations and reliability (Cronbach's alpha) For the Patient Perception of Involvement in Care scale

	Mean	SD	Item-Total Correlation
My doctor asked me whether I agree with his/her decisions.	0.53	0.50	0.37
My doctor gave me a complete explanation for my symptoms or treatment.	0.85	0.36	0.24
My doctor asked me what I believe is causing my symptoms.	0.49	0.50	0.51
My doctors encouraged me to talk about personal concerns related to my symptoms.	0.60	0.49	0.46
My doctor encouraged me to give my opinion about my treatment.	0.60	0.49	0.51
I asked my doctor to explain the treatment or procedure to me in greater detail.	0.72	0.45	0.47
I asked my doctor for recommendations about my symptoms.	0.68	0.47	0.37
I went into great detail about my symptoms.	0.60	0.49	0.34
I asked my doctor a lot of questions about my symptoms.	0.64	0.48	0.47
I suggested a certain kind of treatment to my doctor.	0.22	0.42	0.37
My doctor asked me whether I agree with his/her decisions.	0.12	0.32	0.31
I insisted on a particular kind of test or treatment for my symptoms.	0.13	0.34	0.20
I expressed doubts about the tests or treatment that my doctor recommended.	0.60	0.49	0.45

Patient-provider communication

Patient-provider communication was measured with a 5 item scale reflecting the amount of communication with health care providers. This five item Likert type scale includes a range of responses from “nothing” (1), to “a great deal” (5). Items assess the amount (not the content) of how much a subject tells providers and how much providers tell a subject. For example: “During a typical visit, how much does the doctor usually talk to you about how you are doing since you were treated for breast cancer?” And: “During a typical visit, how much do you tell the doctor about problems you might be having related to your past breast cancer treatment?”

Convergent validity of the patient-provider communication scale is demonstrated by its significant correlation (.34) with the patient perception of involvement in care scale. Construct validity is demonstrated using factor analysis (principle component extraction) demonstrating a single factor solution. Therefore, the summed total of all items was used in analysis. Similar results were found in a sample of men with prostate cancer, also demonstrating a single factor solution with researchers using a total score for patient-provider communication (Mishel et al., 2002a).

Two subjects had missing data on one item. These were replaced with the mean response to that item. The scale was then summed and reflects the total communication between patient and provider, with a higher value reflecting more overall communication. The range of responses was 5-25 with a mean communication score of 16.77 (SD = 4.93), these results are summarized in Table 4.6.

Reliability (Cronbach’s alpha) for the total sample was 0.79 (Table 4.5). Item means, standard deviations and reliabilities are summarized in Table 4.10. Consideration was given to deleting the 5th item reflecting decision-making, but due to the marginal increase in reliability and the fact that decision-making is considered important to patient-provider communication, it was decided to retain this item in the final analysis. Further, examination of item means show that the highest amount of communication is occurring when decisions are being made with the next highest item mean reflecting the fact the doctor tells the patient a moderate amount during the clinical visit.

Table 4. 10 Item Means, standard deviations and reliability (Cronbach's alpha) For the Patient-provider communication scale. (N=203).

Item	Mean	SD	Item-Total Correlation
During a typical visit, how much does the doctor usually talk to you about how you are doing since you were treated for breast cancer?	3.77	1.11	0.55
During a typical visit, how much do the nurses and other treatment staff usually talk to you about how you are doing since you were treated for breast cancer?	2.80	1.30	0.61
During a typical visit, how much do you tell the doctor about problems you might be having related to your past breast cancer treatment?	3.47	1.29	0.70
During a typical visit, how much do you usually tell the nurses and treatment staff about problems you might be having related to your past breast cancer treatment?	2.79	1.31	0.69
During a typical visit, how much do you help with decisions about your care?	3.92	1.17	0.36

Control Preferences Scale

The Control Preferences Scale (Degner et al., 1997) is a series of 5 cards illustrating a range of decision-making preferences. A passive style indicates that the patient wishes the provider to make all decisions. A collaborative preference indicates equal decision-making input and an active style reflects the desire of the patient to make all decisions independently of the provider. Responses reflect a continuum from A, the most active decision making role, to E, the most passive decision-making role. C reflects a collaborative midpoint in decision-making between patient and provider where both participants have an equal input in decision-making.

Responses on the Control Preferences Scale were recoded numerically as A=1, B=2, C=3, D=4, E=5. The discrepancy between actual decision-making role and desired decision-making role was calculated by subtracting a woman's desired decision-making role from her attained decision-making role. The most frequently desired decision-making role with providers was collaborative, desired by 49% of women. Very few women desired to make all their decisions independently (4%), an active decision-making role or to delegate all their decisions to their provider (3%), a passive decision-making role. Women were not always able to achieve their desired decision-making role. A T-test showed a significant difference between desired and attained roles (Table 4.11). Results for desired, attained, and the discrepancy between roles are summarized in 4.12, 4.13 and 4.14. Discrepancy scores can range from –4 to +4, with a zero discrepancy score indicates no difference between a woman's desired decision-making role and attained decision-making role.

Based on Coombs unfolding theory, this scale was deemed reliable for this sample because there was a reversal in these data set. (ABCDE and EDCBA) and 50% plus one or more responses fell within the original metric of 11 valid responses as suggested by Degner (Degner et al., 1997). For this sample, 71.4% of responses were valid, falling within the original metric.

Table 4.11 Comparison of desired versus attained role preference

Source	df	t	Sig. (2-tailed)	Mean Difference	95% C I Lower	95% C I Upper
desired role	202	49.03	.000	2.84	2.73	2.96
attained role	202	46.97	.000	3.06	2.94	3.19

$p \leq 0.001$

Table 4.12. Desired decision-making role

	Frequency	%
Active (A)	8	3.90
Active/Collaborative (B)	58	28.6
Collaborative (C)	99	48.8
Passive/Collaborative (D)	33	16.3
Passive (E)	5	2.50
Total	203	100

Table 4.13 Attained decision-making role

	Frequency	%
Active (A)	7	3.40
Active/Collaborative (B)	46	22.7
Collaborative (C)	90	44.5
Passive/Collaborative (D)	46	22.7
Passive (E)	14	6.90
Total	203	100

Table 4.14 Discrepancy between actual decision-making role and desired decision-making role, [attained decision-making role minus desired decision-making role].

Score	Frequency	%
-2	10	4.12
-1	41	20.2
0	98	48.3
1	43	21.2
2	8	3.9
3	2	1.0
4	1	0.5
Total	203	100

	Range	Mean	SD
Total Sample	-2 - 4	0.04	0.97

A negative value indicates that attained decision-making role is more active than desired.
A positive value indicates that attained decision-making role is more passive than desired.

Note: Totals may add up to more than 100 percent due to rounding.

Mishel Uncertainty in Illness Scale

The Mishel Uncertainty In Illness Scale- Survivor Version, is a 22 item, Likert formatted scale ranging from strongly agree to strongly disagree. Item scores were summed to reflect a woman's total level of uncertainty. Higher scores reflect greater levels of uncertainty. Items were adapted by Mishel to reflect concerns experienced by survivors as opposed to those experiencing acute illness events and reflect issues that women may feel uncertain about such as: "I have a lot of questions without answers," and, "It is unknown whether I will have long-term problems from my treatment." Range of uncertainty scores in this sample was 29-86 with a mean of 56.8 (Table 4.5). Average item uncertainty level was 2.58 with a range of 1.32-3.91 (Table 4.11). The reliability (Cronbach's alpha) for the entire sample was 0.80 (Table 4.5).

Convergent validity of this scale has been ascertained through use among patients with cancer, (Mishel et al., 2002a), menopausal women (Lemaire & Lenz, 1995), and among cardiac patients (Carroll, Hamilton, & McGovern, 1999; White & Frasure-Smith, 1995) Taken together, results of current and previous research demonstrate the concurrent validity of the Uncertainty in Illness scale in different populations. In this sample of older breast cancer survivors, convergent validity is supported by the significant positive correlation with both measures of emotional distress. Factor analysis (principle component extraction with promax rotation) demonstrated a 4 factor solution with eigenvalues above 1.0 and factor loadings of .421 or higher.

Table. 4.15 Item Means, standard deviations and reliability (Cronbach's alpha) For Mishel's Uncertainty in Illness scale (N=203).

Item	Mean	SD	Item-Total Correlation
I don't know if anything is wrong with me.	2.95	1.18	0.33
I have a lot of questions without answers.	2.54	1.13	0.49
I don't know if my cancer will ever come back.	3.75	0.91	0.20
I don't know how bad my discomfort might be.	3.57	1.06	0.33
The explanations they give me about my treatment side-effects do not make sense to me.	2.19	0.89	0.43
The long-term effect of my treatment is clear to me.	2.26	0.91	0.31
It is unknown whether I will have long-term problems from my treatment.	3.18	1.05	0.21
I understand everything explained to me.	2.37	0.96	0.36
The doctors say things to me that are confusing.	2.42	1.00	0.51
The long-term effects of my treatment are too complex to figure out.	2.47	0.95	0.46

Table. 4.15 Item Means, standard deviations and reliability (Cronbach's alpha) For Mishel's Uncertainty in Illness scale (N=203). (Continued)

Item	Mean	SD	Item-Total Correlation
My treatment side-effects keep changing. I have good and bad days.	2.23	1.05	0.48
I have been told different things about what my treatment side-effects mean.	2.10	0.84	0.44
I do not know what is going to happen to me.	3.40	1.15	0.41
The results of my mammography are inconsistent from one year to the next.	2.16	1.62	0.16
The long-term benefit from the treatment is unknown.	2.83	1.15	0.43
I'm certain they will not find anything else wrong with me.	3.36	1.03	0.23
The treatment I received is known to be successful.	1.878	0.57	0.29
They have not given me specific information about my long-term health.	2.80	1.12	0.40
I know how serious my breast cancer was.	1.77	0.67	0.09
The doctors and nurses use words that I can understand.	2.11	0.91	0.25

Profile of mood states

The dependent variable of mood state was measured with the Profile of Mood States (POMS) (Curran et al., 1995). This scale assesses the moods and feelings women may experience such as sad, confused, grouchy, as well as lively, cheerful, and energetic. Responses range from 0 (not at all) to 4 (extremely) on this 37 item Likert type scale. Scores were summed, potentially ranging from 0-148. Higher scores indicate higher levels of distress.

The mean distress score for this sample was 31.7 (SD = 17.34, range 0-101) indicating a low level of distress (Table 4.6). Mast (1998b) found similar distress scores (mean = 37.42, SD = 23.68) using the POMS –SF in a sample of 109 women 1-6 years post treatment. Considering the current sample is age 50 and older, these low distress scores are in keeping with research that has found older women have less distress than younger women (Cameron & Horsburgh, 1998; Sammarco, 2001a). Item means and standard deviations are summarized in Table 4.16. The reliability (Cronbach's alpha) for the POMS was 0.93 for the total sample (Table 4.5). Convergent validity of this scale is supported by a positive correlation with both uncertainty and troublesome thoughts of recurrence.

Table 4.16 Item Means, standard deviations and reliability (Cronbach's alpha) For The Profile of Mood States. (N=203).

Item	Mean	Std. Dev.	Item-Total Correlation	Alpha if Item Deleted
Tense	1.15	1.05	0.59	0.92
Angry	0.43	0.76	0.33	0.93
Worn out	1.39	1.27	0.53	0.93
Unhappy	0.53	0.87	0.62	0.92
Lively	1.89	1.10	0.44	0.93
Confused	0.48	0.81	0.43	0.93
Peeved	0.47	0.85	0.44	0.93
Sad	0.70	0.95	0.54	0.93
Active	1.56	1.08	0.37	0.93
On edge	0.64	0.84	0.62	0.92
Grouchy	0.41	0.70	0.54	0.93
Unable to concentrate	0.73	0.95	0.59	0.92
Blue	0.52	0.77	0.62	0.92
Energetic	2.07	1.13	0.43	0.93
Hopeless	0.14	0.43	0.44	0.93
Uneasy	0.52	0.73	0.58	0.92
Restless	0.75	0.94	0.43	0.93
Fatigued	1.46	1.10	0.55	0.93
Annoyed	0.66	0.93	0.52	0.93
Discouraged	0.49	0.70	0.64	0.92

Table 4.16 Item Means, standard deviations and reliability (Cronbach's alpha) For The Profile of Mood States. (N=203) (continued).

	Mean	Std. Dev.	Item-Total Correlation	Alpha if Item Deleted
Resentful	0.29	0.69	0.35	0.93
Nervous	0.72	0.84	0.51	0.93
Exhausted	1.19	1.15	0.57	0.92
Anxious	0.85	0.82	0.47	0.93
Helpless	0.25	0.65	0.53	0.93
Weary	0.72	0.92	0.66	0.92
Bewildered	0.25	0.53	0.47	0.93
Furious	0.18	0.53	0.44	0.93
Full of pep	2.29	1.09	0.46	0.93
Worthless	0.16	0.57	0.52	0.93
Forgetful	1.05	0.99	0.44	0.93
Vigorous	2.54	1.10	0.27	0.93
Uncertain about things	0.94	0.93	0.58	0.92
Bushed	1.12	1.13	0.54	0.93

Index of troublesome thoughts

The other dependent variable, troublesome thoughts of recurrence was originally modified to measure a woman's troublesome thought of breast cancer recurrence (Gil et al., 1996). Item scores were summed to reflect an overall assessment of the total amount of troublesome thoughts of recurrence with higher scores indicating more troublesome thoughts of recurrence. Reliability (coefficient alpha) for the index of troublesome thoughts was 0.74 (Table 4.5). Items assessed thoughts a woman might have, such as: This pain could only mean cancer, or, If her cancer has spread, then mine will also. Women ranged from a total score of 13-46 with a mean of 21.54 (SD = 6.64), (Table 4.6). The range of item scores in this sample was 1-3.54 with a mean score of 1.65. Item means and standard deviations and reliabilities are presented in Table 4.17.

This measure has been used in many different populations, demonstrating content and concurrent validity. In this sample, convergent validity is supported by a positive correlation with troublesome thoughts of recurrence and uncertainty.

Table 4.17 Item Means, standard deviations and reliability (Cronbach's alpha) for The Index of Troublesome Thoughts of Recurrence. (N=203).

Item	Mean	SD	Item-Total Correlation
The doctor might be wrong.	2.03	0.92	0.37
My disease is worse than hers.	1.39	0.69	0.50
If her cancer has spread, then mine will also.	1.54	0.86	0.57
My husband (partner) will think I'm foolish for paying so much attention to my body.	1.42	0.87	0.30
No one wants to hear about my fear of recurrence.	1.97	1.10	0.42
It is not fair that I have to live with this constant worry about recurrence.	1.50	0.84	0.53
The headache or backache (or any other new physical problem) is getting worse, it must be cancer.	1.87	1.02	0.57
This pain could only mean cancer.	1.66	0.91	0.55
know the doctor is not telling me the truth.	1.28	0.67	0.32
They are taking too long to read the results of my test, it must be bad.	1.87	1.05	0.49
They know something they are not telling me.	1.40	0.73	0.46
I am going to die from breast cancer.	1.50	0.79	0.57
I am helpless to do anything about the future course of my disease.	1.52	0.92	0.38

Moderators

To test the moderating effects of age and ethnicity on the relationship between structure provider variables and stimuli frame variables, individual interaction terms were created. Ethnicity was initially recoded 0,1, for African American women and Caucasian women respectively. Variables consisting of the product of either age or ethnicity and the five structure provider indicators were created. Finally, paths were created between these interaction terms and the two indicators of the stimuli frame. As an example, to test the moderating effect of age on relationship between education and symptom bother, an interaction term was created by multiplying age by education, then testing a path between this interaction variable and symptom bother.

To avoid problems with multi-colinearity of the independent variables due to the inclusion of interaction terms, centered variables were created by subtracting the variable mean from the variable value. This process results in a revised sample mean of zero for the newly centered variable but does not impact the level of significance of the interaction term (Aiken & West, 1991a).

Residual Analysis

Path analysis assumes that all variables are measured without error, that all relevant variables have been included in the model, and that there is a one way causal flow (a recursive model) (Mason-Hawkes & Holm, 1989; Norris, 2001a; Pedhazer & Schmelkin, 1991; Norris, 2001a; Pedhazer E.J., 1997). Although path analysis is a component of Structural Equation Modeling (SEM), an advantage of using SEM over path analysis is that SEM does not require a recursive model. Similar to regression and path analysis, SEM requires normally distributed, linear, and additive variables (Mason-Hawkes & Holm, 1989; Norris, 2001a; Pedhazer & Schmelkin, 1991; Pedhazer E.J., 1997). Examination of these data for skewness and kurtosis was performed showing that data were normally distributed using a range of –2 to +2 (Table 4.18). All data except the distribution of the POMS met this assumption. However, since some authors use a range of –3 to + 3 (Bollen, 1989) these data were deemed acceptably distributed. Symptom bother was slightly more peaked than other variables, however, this was expected. Residuals (Cooks D and leverage) of centered variables and dependent variables were examined graphically and found to be normally distributed. Thus, the residual analysis showed these data met the necessary assumptions.

Table 4.18 Skewness and Kurtosis of Variables in the Structural Equation Model

Variable	Skewness		Kurtosis	
	Statistic	Std. Error	Statistic	Std. Error
Age	0.71	0.17	0.03	0.34
Education	-0.32	0.17	1.08	0.34
Patient Perception of Involvement in Care	-0.12	0.17	-0.75	0.34
Patient-provider Communication	-0.36	0.17	-0.30	0.34
Attained role	0.12	0.17	-0.21	0.34
Desired role	0.13	0.17	0.10	0.34
Discrepancy between roles	0.45	0.17	1.44	0.34
Symptom bother	1.80	0.17	3.29	0.34
Symptom number	0.71	0.17	-0.24	0.34
Uncertainty	0.05	0.17	0.16	0.34
Profile of Mood states	1.11	0.17	2.45	0.34
Index of Troublesome Thoughts	0.96	0.17	0.90	0.34

Since results on all measures were similar for both African American and Caucasian women, and additionally, as were discussed later in this chapter, ethnicity did not retain significance in the original model, all analyses were computed on the total sample of 203 women.

Test of the Model

SEM tests the hypothesized relationships between variables and is most meaningful when these relationships are based on theory, due to the need for imposing an hypothesized linear order on selected variables (Norris, 2001a; Pedhazer & Schmelkin, 1991; Pedhazer, 1997). Theory suggests the order of the proposed relationships as well as aiding in interpreting results.The theory guiding this model was Uncertainty in Illness theory (Mishel, 1988).

The decision to use only manifest variables was made to facilitate explanation and interpretation of interaction findings. A single indicator approach was selected to test interaction effects following Jaccard & Wan (1995), Joreskog & Yang (1996), and Joreskog (1998). This approach reduces the number of constraints and potential problems with normality. Additionally since there are fewer parameters to estimate, power is increased, an advantage when using structural equation modeling techniques with smaller samples.

Because only manifest variables were utilized, error in the model represents the actual decision-making role measurement error of the regression equations associated with parameters, rather than the error associated with the measurement of a concept, as would be the case in a model employing latent variables. Thus although the measurement error inherent in the underlying concepts has not been accounted for in the manifest variables, due to the fact that scale reliabilites are high, it can be assumed that measurement error is minimal.

Prior to model reduction, a correlation matrix was constructed for all continuous variables (Table 4.19). With the exception of the high correlation between symptom number and bother (.83), all correlations were small to moderate. Since symptom number and bother are two indicators of the same independent variable, stimuli frame, this was expected, and errors were subsequently correlated in the structural equation model. The positive correlation between the two indicators of Emotional Well-Being, the dependent variable, was small (.24), but because these variables were conceptualized to be similar indicators of the dependent variable, their errors were also correlated in the structural equation model. However, these two indicators were thought to represent related but separate components of emotional well-being. This assumption is supported based on their small but positive correlation.

In SEM, parameters are simultaneously estimated, then the adequacy of the fit of the model to these data are provided. SEM uses maximum likelihood estimation, allowing calculation of the fit of direct and indirect path coefficients, unlike path analysis, which employs ordinary least square estimates and does not provide an overall fit of direct and indirect paths (Aiken & West, 1991b). Fit indices indicate the similarity between the covariance matrix of the estimated model and the sample data. For ease in interpretation, standardized path coefficients were used, facilitating comparison by representing results using the same unit of measurement (Polit, 1996). Each variable was entered as an observed predictor in the model. The interpretation of the relationships between variables as suggested by the parameters of the model is only meaningful if these data fit the model, and thus can be considered consistent with the sample covariance matrix representing the population under consideration (Hoyle, 1995).

Model Fit

The initial model was over-identified, (the number of estimable parameters is less than the number of data points) reflecting 42 degrees of freedom. Thus, the model can be tested (Byrne, 2001). Model analysis was completed using Analysis of Moment Software (AMOS) (Chicago, IL). The process of model reduction was accomplished by assessing the standardized path coefficients and systematically deleting the path with the smallest critical ratio (indicating non-significance), until all retained paths had achieved a critical ratio of 1.96 or higher (indicating significance), (Byrne, 2001).

Model fit was assessed using multiple indices to determine goodness of fit. After each calculation of the model, the chi-square value was examined. If the model fits these data well the chi-square is small with $p > .05$. indicating that the model does not significantly differ from these data. Next, the Root Mean Square Error of Approximation (RMSEA) was evaluated. A RMSEA value below 0.05 indicates a good fit of the model to these data. Additionally, the closeness of fit (as opposed to goodness of fit) of the RMSEA, indicating a good fit in this *population* (testing the hypothesis that $p \leq .05$) was examined. Recommended value for this test is $p > .50$ (Byrne, 2001 pg 85). Subsequently, the Normed Fit Index and the Relative Fit Index were evaluated. Values between 0.95 and 1.000 indicate an acceptable fit of these data to the model. The Incremental Fit Index accounts for the degrees of freedom in the model, accounting for the parsimony of the model. Finally the R^2 was examined. R^2 is a measure of a model's fit or adequacy in representing these data and is the square of the correlation between the observed and predicted scores (Maxwell & Delaney, 2000). R^2 is a useful descriptive index and does not increase with sample size (Maxwell & Delaney, 2000), unlike chi square indices of model fit (Norris, 2001b) .

After fit indices were examined, the modification indices were examined before deleting each nonsignificant path, however, there were no suggested alternative paths to improve model fit. Subsequently, the path with the lowest nonsignificant critical ratio was deleted and the model was rerun. The process of examining fit indices, modification indices and path deletion was repeated until all remaining paths achieved significance. The original model was presented as Figure 3.2. Path coefficients, standard errors, and critical ratios, of the original model are presented in Table 4.20.

Table 4.19. Pearson Correlation Matrix of variables in the proposed model.

	Ethnicity	Education	Age	Pt-Prov Comm	PPIC	Desired Role	Attained Role	Discrepancy	Symptom Number	Symptom Bother	Uncertainty	POMS
Ethnicity												
Education	-0.25**											
Age	-0.06	-0.11										
Patient-provider communication	0.04	-0.06	-0.30**									
Patient perception of involvement in care	0.07	-0.02	-0.28**	0.34**								
Desired role	0.13	-0.15	0.22**	-0.11	-0.10							
Attained role	0.07	-0.21**	0.20**	-0.11	-0.16*	0.44**						
Discrepancy	-0.14	0.05	-0.03	0.00	-0.06	-0.02	0.06					
Symptom number	-0.06	0.01	-0.33**	0.06	0.10	-0.02	-0.14*	0.05				
Symptom Bother	0.00	0.04	-0.30**	0.04	0.04	-0.02	-0.15*	0.08	0.83**			
Uncertainty	0.01	-0.16*	0.00	-0.02	0.00	-0.09	-0.02	0.05	0.34**	0.38**		
POMS	-0.05	0.05	-0.02	-0.06	0.05	-0.04	-0.05	0.02	0.26**	0.33**	0.26**	
Troublesome thoughts	-0.14	0.07	-0.26*	0.22**	0.13	-0.13	-0.09	0.09	0.40**	0.43**	0.39**	0.24**

**$p \leq .01$

* $p \leq 0.05$

Table 4.20. Original model estimates, critical ratios and significance (unstandardized).

	Symptom Number			Symptom Bother			Uncertainty			POMS			Troublesome Thoughts		
	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.
Education	0.17	0.15	1.17	0.03	0.02	1.48	-0.57	0.21	-2.70*	0.36	0.39	0.94	0.17	0.13	1.23
Communication	-0.02	0.11	-0.21	-0.01	0.02	-0.50	-0.13	0.14	-0.92	-0.31	0.01	-0.95	0.22	0.09	2.45**
PPIC	0.00	0.17	0.00	-0.01	0.03	-0.20	0.04	0.22	0.18	0.40	0.40	0.99	0.18	0.14	1.27
Attained role	-0.52	0.56	-0.94	-0.06	0.09	-0.65	0.32	0.78	0.41	0.68	1.40	0.48	0.32	0.49	0.64
Desired role	0.50	0.60	8.38	0.01	0.09	0.12	-1.48	0.85	-1.73	-0.63	1.54	-0.41	-0.41	0.54	-0.75
Discrepancy	0.04	0.44	0.09	-0.02	0.07	-0.35	0.27	0.65	0.42	-0.30	1.17	-0.25	0.16	0.41	0.40
Age	-0.13	0.03	-4.71**	-0.02	0.01	-4.03**									
Ethnicity	0.72	0.56	1.29	0.02	0.09	0.17									
Age X education	-0.01	0.01	-0.78	0.00	0.00	-1.38									
Age X Communication	0.01	0.01	1.14	0.00	0.00	0.34									
Age X PPIC	0.00	0.01	0.16	0.00	0.00	0.47									
Age X Attained role	-0.04	0.04	-0.98	-0.01	0.01	-1.00									
Age X desired role	0.00	0.05	0.03	0.00	0.01	-0.25									
Age X Discrepancy	0.01	0.03	0.40	0.00	0.01	0.00									
Ethnicity X education	-0.40	0.19	-2.11*	-0.06	0.03	-2.08*									
Ethnicity X Communication	-0.06	0.13	-0.45	0.00	0.02	-0.17									
Ethnicity X PPIC	0.00	0.20	0.02	-0.01	0.03	-0.27									
Ethnicity X desired role	0.06	0.73	0.08	0.08	0.11	0.71									
Ethnicity X Attained role	-0.08	0.71	-0.11	-0.07	0.11	-0.64									
Ethnicity X Discrepancy	0.30	0.57	0.52	0.14	0.09	1.62									
Symptom number							0.18	0.28	0.57	-0.266	0.52	-0.51	0.08	0.18	0.45
Symptom bother							5.42	1.87	2.88**	9.06	3.43	2.63**	2.43	1.21	2.00*
Uncertainty										0.33	0.12	2.61**	0.21	0.04	4.11**
R2	0.176			0.158			0.183			0.15			0.28		

**p≤.01, * p≤ 0.05

Analysis of the Research questions

This section presents the results of the test of the model, answering the original research questions presented in Ch 3. The first series of research questions assesses the influence of the stimuli frame operationalized as symptom number and symptom bother on Uncertainty.

Research question A: Does the stimuli frame influence the level of uncertainty of older breast cancer survivors?

Two indices of the stimuli frame, symptom number and symptom bother were evaluated for their influence on uncertainty. The variable symptom number did not significantly influence uncertainty in this sample of older breast cancer survivors and was ultimately dropped from the original model. However, symptom bother, the other measure of stimuli frame was significant, positively influencing uncertainty. Thus, as symptom bother increased, uncertainty also increased in this sample.

Research question B: Does the stimuli frame influence emotional well-being in older breast cancer survivors?

In this sample of older breast cancer survivors there was no relationship between symptom number and either mood state or troublesome thoughts of recurrence. The path coefficient for the relationship between symptom bother and mood state showed that symptom bother was positively associated with mood state. Findings showed that as bother increased, women experienced a worsening mood state. Additionally analysis showed symptom bother was positively associated with troublesome thoughts of recurrence. As the bother attributed to symptoms increased, so did a woman's troublesome thoughts of recurrence.

Research question C: Do structure providers influence the stimuli frame in older breast cancer survivors?

This series of research questions asked if structure providers (operationalized as education, patient-provider communication, patient perception of involvement in care, desired decision-making role, actual decision-making role, and the discrepancy between these roles were associated with the stimuli frame (operationalized as symptom number and symptom bother). Symptom number was not significantly associated with any structure provider variables as demonstrated by path coefficients failing to achieve a critical ratio of 1.96 or higher. Therefore, there is no relationship between these variables and symptom number.

There was also no significant relationship between education, patient-provider communication, and symptom bother. Therefore, the hypothesized relationship between structure providers and the stimuli frame was not supported in this sample. The remaining four communication measures were independently evaluated for their association with symptom number and symptom bother and found to be nonsignificant. The patients perception of involvement in care (patient perception of involvement in care), and the three measures of the Control Preferences Scale (CPS), desired decision-making role, actual decision-making role, and the discrepancy between these roles did not achieve significance with any endogenous variable and were subsequently dropped from the original model.

Research question D: What factors moderate the relationship between structure providers and the stimuli frame in older breast cancer survivors?

The fourth series of research questions assessed the moderating influence of age and ethnicity on the relationship between the stimuli frame (symptom number and symptom bother), and structure providers (education, patient-provider communication, patient perception of involvement in care, desired decision-making role, actual decision-making role and the discrepancy between these roles). This was evaluated by creating a set of interaction terms reflecting the product of either age or ethnicity and the five exogenous structure provider variables, then testing a path between these terms and the stimuli frame variable of symptom number and symptom bother.

Analysis of the SEM model showed partial support for an interaction between the endogenous variables of symptom number and bother, and the interaction of ethnicity X education. Additionally, the correlation matrix demonstrated a moderate correlation (.25 $p \leq .01$) between ethnicity and education. This suggests an association between ethnicity and educational level, which subsequently affects a woman's symptoms and associated symptom bother. Additionally, age significantly influenced both symptom number and bother, however there were no significant interactions between age and any other variable with respect to symptom number and symptom bother in the original model.

As testing of the model progressed, (deleting nonsignificant paths using the criteria of a critical ration of 1.96 or greater to indicate significance at the level of $p \leq .05$), the initially significant interaction effect between ethnicity X education, and symptom number and bother did not retain significance and was ultimately deleted from the original model. Thus, all paths testing interactions between age, ethnicity, and structure provider variables (moderating effects of age and ethnicity on the association between the stimuli frame and structure providers) were deleted from the original model.

However, due to the need to include first order terms as well as interaction terms in the structural equation model, age and ethnicity were also tested as independent predictors of the endogenous variables. Results showed that ethnicity was not associated with any other variable and was ultimately dropped from the model due to nonsignificance. Age, on the other hand, was significantly and directly associated with symptom bother and symptom number suggesting that as age increases, women are less bothered by their experienced symptoms. No other significant direct effects of age were noted in the original model.

Research question E: Do structure providers influence uncertainty in older breast cancer survivors?

This series of research questions tested the direct effect of the six structure provider variables on uncertainty. Results showed that the only significant path was the relationship between education and uncertainty. Education directly and inversely predicted uncertainty. As the amount of education increases, the amount of uncertainty decreases. None of the other five structure provider variables representing the concept of a credible authority and operationalized as the process of communication achieved significance when tested for a relationship with uncertainty.

Research question F. Does uncertainty influence the emotional well-being of older breast cancer survivors?

This series of questions tested the relationships between uncertainty, mood state, and troublesome thoughts of recurrence. Uncertainty was directly and positively associated with both mood state and troublesome thoughts of recurrence. These findings show that as uncertainty increases, women experience a worsening mood state as well as increased thoughts about the possibility of a recurrence.

Research question G: Do structure providers influence the emotional well-being of older breast cancer survivors?

The seventh series of research questions assessed the influence of structure providers (education, patient-provider communication, patient perception of involvement in care, and a woman's desired decision-making role and actual decision-making role and the discrepancy between these roles) on the emotional well-being (mood state and troublesome thoughts of recurrence) of older breast cancer survivors. The path coefficient between patient-provider communication and troublesome thoughts of recurrence showed that patient-provider communication positively and directly predicted the number of troublesome thoughts of recurrence. As communication with providers increased, so did a woman's thoughts about recurrence.

Research question H: Does uncertainty mediate the relationship between structure providers and emotional well-being in older breast cancer survivors?

The last series of research questions assessed the mediating influence of uncertainty on the relationship between structure providers (education, patient-provider communication, patient perception of involvement in care, desired decision-making role, actual decision-making role, and the discrepancy between these roles) and emotional well-being (mood state and troublesome thoughts of recurrence). Findings showed that uncertainty mediated the relationship between education and mood state. Uncertainty also mediated the relationship between education and troublesome thoughts of recurrence. Findings show that indirectly education was associated with troublesome thoughts of recurrence. Therefore, the original model suggested that women with lower education experienced higher uncertainty, as well as worse mood states and increased troublesome thoughts of recurrence.

The Alternative Reduced Model

An alternative, more parsimonious model was suggested as result of model testing. The alternative reduced model is presented in Figure 4.3. Direct and indirect effects are summarized in Table 4.21 and critical ratios and significance levels for each relationship are summarized in Table 4.22. When the critical ratios of all paths had achieved significance, fit indices were evaluated and deemed acceptable. The RMSEA in the alternative reduced model was 0.046 indicating a very good fit of these data to the reduced alternative model. Additionally, the reported 90% confidence interval around the RMSEA is 0.00-0.098. This is a narrow interval therefore it can be assumed that there is good precision of this model fit and it is reasonable to assume that the true RMSEA within a population of older breast cancer survivors would fall within this range. Finally, because the *closeness of fit* of the RMSEA is very close to the recommendation of >0.50 (0.487) (Byrne, 2001) pg 85, (testing the hypothesis of a RMSEA of .05 or less in a *population* of breast cancer survivors) it is further concluded that the alternative model fits these data.

The Incremental Fit index of the alternative reduced model is .996, which is within the recommended value of 0.95 – 1.000, again indicating good fit. Similarly, the Tucker-Lewis Co-efficient of the alternative reduced model is .988 also indicating good model fit, since this value is also within the recommended values of 0.95 – 1.000.

Although symptom number ultimately did not attain a significant relationship with any other variable and was dropped from the original model, symptom bother remained highly significant. In the reduced alternative model, symptom bother ultimately accounted for 39% of the variance in uncertainty, (Table 4.21). The path coefficient for the relationship between symptom bother and mood state showed that symptom bother was positively associated with mood state directly accounting for 27%

of the variance of the mood state of older breast cancer survivors (Table 4.21). Lastly, analysis showed symptom bother was positively associated with troublesome thoughts of recurrence directly accounting for 31% of the variance in troublesome thoughts of recurrence for older breast cancer survivors. As the bother attributed to symptoms increased, so did a woman's troublesome thoughts of recurrence.

The alternative model demonstrates the lack of any retained moderating effects of either age or ethnicity (Figure 4.3). However, due to the need to include first order terms as well as interaction terms in the structural equation model age and ethnicity were also tested as independent predictors of the endogenous variables. Results showed that ethnicity did not achieve significance and was ultimately dropped from the original model. Age, on the other hand, was significantly and directly associated with symptom bother accounting for 30% of the variance in symptom bother (Table 4.21). As age increased, women were less bothered by their experienced symptoms. Further, indirectly, older women also experienced less uncertainty (11% of the variance in uncertainty), a better mood state (9% of the variance in mood state), and fewer troublesome thoughts of recurrence (12% of the variance in troublesome thoughts of recurrence) thru the association of age with the amount of symptom bother. Thus, when assessing direct and indirect effects, age had the largest impact on emotional well-being of any independent variable accounting for up to 63% of the variance in the alternative model (Table 4.21).

In the alternative model, education directly and inversely predicts uncertainty, accounting for 18% of the variance in uncertainty (Table 4.21). As the amount of education increases the amount of uncertainty decreases. Further, education had negative indirect effects on both mood state and troublesome thoughts of recurrence (Table 4.21). Findings showed that uncertainty mediated the relationship between education and mood state (Figure 4.3). Summing the direct and indirect paths, education accounted for 21% of the variance in mood state (Table 4.21). Uncertainty also mediated the relationship between education and troublesome thoughts of recurrence. Findings show that indirectly education accounts for 23% of the variance in troublesome thoughts of recurrence. Thus, women with lower education experience higher uncertainty, as well as worse mood states and increased negative troublesome thoughts of recurrence.

Following the model, uncertainty was directly and positively associated with mood state accounting for 16% of the variance in the mood state of older breast cancer survivors, and with troublesome thoughts of recurrence, accounting for 27% of the variance in the amount of troublesome thoughts of recurrence in older breast cancer survivors (Table 4.21). These findings show that as uncertainty increases, women experience a worsening mood state as well as increased thoughts about the possibility of a recurrence.

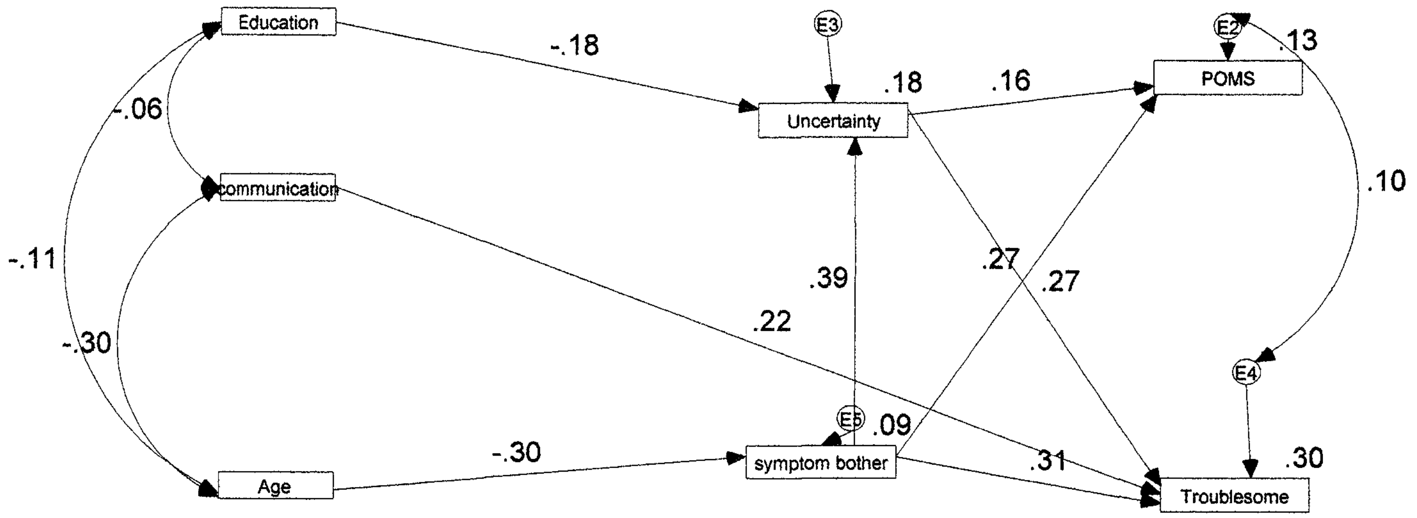
Finally, the path coefficient between patient-provider communication and troublesome thoughts of recurrence in the alternative model shows that patient-provider communication positively and directly predicts the number of troublesome thoughts of recurrence, accounting for 22% of the variance in the amount of troublesome thoughts. As communication with providers increased, so did a woman's thoughts about recurrence (Table 4.21).

Table 4.21 Summary of total, direct and indirect effects of reduced alternative model.

	Age	Education	Symptom bother	Patient-provider Communication	Uncertainty
Standardized Total Effects - Estimates					
Symptom bother	-0.30	0.00	0.00	0.00	0.00
Uncertainty	-0.11	-0.18	0.39	0.00	0.00
Troublesome thoughts of recurrence	-0.12	-0.05	0.42	0.22	0.27
POMS	-0.10	-0.03	0.33	0.00	0.16
Standardized Direct Effects - Estimates					
Symptom bother	-0.30	0.00	0.00	0.00	0.00
Uncertainty	0.00	-0.18	0.39	0.00	0.00
Troublesome thoughts of recurrence	0.00	0.00	0.31	0.22	0.27
POMS	0.00	0.00	0.27	0.00	0.16
Standardized Indirect Effects - Estimates					
Symptom bother	0.00	0.00	0.00	0.00	0.00
Uncertainty	-0.11	0.00	0.00	0.00	0.00
Troublesome thoughts of recurrence	-0.12	-0.05	0.11	0.00	0.00
POMS	-0.10	-0.03	0.06	0.00	0.00

Figure 4.3. Reduced Alternative Model

Path model of Emotional Well-Being in Breast Cancer Survivors



Chi Square =12.902
Degrees of Freedom =9
Norm Fit Index = .988
Relative Fit Index = .963
Incremental Fit Index =.996
Tucker-Lewis Co-efficient =.988
RMSEA =.046

Table 4.22 Reduced alternative model estimates, critical ratios and significance (unstandardized).

	Symptom Bother			Uncertainty			POMS			Troublesome Thoughts		
	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.	Estimate	S.E.	C.R.
Education				-0.528	0.004	-2.531**						
Communication										0.274	0.007	3.205**
Age	-0.018	0.004	-4.709**									
Symptom bother							7.580	0.055	3.698**	2.914	0.056	4.045**
Uncertainty	6.277	0.048	5.906**				0.319	0.074	2.570**	0.212	0.074	4.111**
R2		0.088			0.175			0.130			0.304	

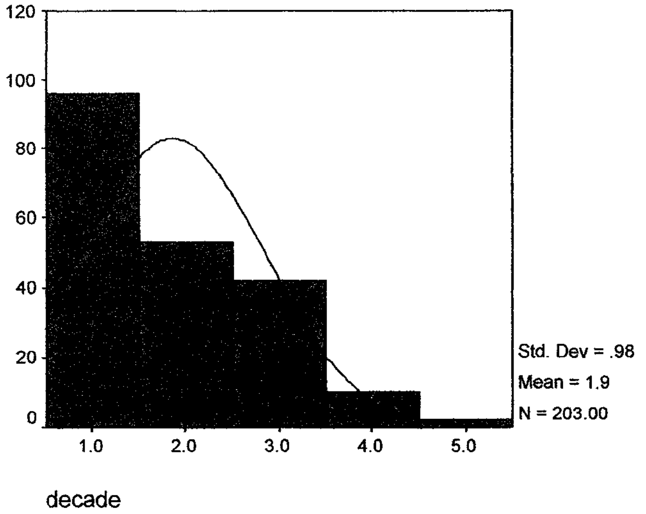
**$P \leq .01$

Additional Analysis

To completely test the influence of a patient's preference for involvement in care, the model was tested with each of the three subscales of the patient preference for involvement in care scale, doctor facilitation, patient information, and decision-making. The model was tested three times substituting each subscale in turn for the total scale. Evaluation of these three alternative models did not result in an improved model fit or additional significant path coefficients, therefore the entire patient perception of involvement in care scale was tested as part of the original model.

Due to the large contribution of age, a closer examination of this variable showed that while all women were over 50 years, the median age was 61years. Mean, median, mode and distribution were examined and are summarized in Tables 4.22 and 4.23. Inspection of these data show the distribution is slightly skewed to the left (Figure 4.5). Forty seven percent of respondents were between 50 and 60 years. Only 6% were age 80 or older. 75% of women were between age 50 and 70. Thus, while an age span of 46 years is represented, the sample is predominantly between 50-80 with the largest number of women age 50-60 years.

Figure 4.4 Distribution of age by decade



1=50-59 years, 2=60-69 years, 3=70-79 years, 4=80-89 year, 5=90-96 years

Table 4.23. Mean, median, mode and distribution of Age. N=203

Mean	63.33
Median	61.00
Mode	54.00
Std. Deviation	9.60
Skewness	0.71
Std. Error of Skewness	0.17
Kurtosis	0.03
Std. Error of Kurtosis	0.34

Table 4.24 Frequency of Age by decades N=203

Age	Frequency	Percent
50-59	96	47.30
60-69	53	26.10
70-79	42	20.70
80-89	10	4.12
90-96	2	1.00
Total	203	100.00

Summary

In summary, the original model was reduced by eliminating nonsignificant paths, using a significant critical ratio of 1.96. Variables associated with these nonsignificant paths were eliminated from the model. Eliminated variables were: patients preference for involvement in care, desired decision-making role, actual decision-making role, the discrepancy between desired decision-making role and actual decision-making role, ethnicity, and all interaction terms. An alternative model retaining only significant paths is presented, demonstrating the direct effect of age on the stimuli frame.

The most striking finding was the large indirect effect of age on emotional well-being and uncertainty, dependent on the experienced amount of symptom bother. Education also explained a higher than expected percentage of the variance in emotional well-being due to its association with uncertainty. Conversely, the expected effect of the communication variables on uncertainty was not found. Further, the results showed an unexpected finding of increased patient-provider communication predicting increased troublesome thoughts of recurrence.

CHAPTER FIVE: DISCUSSION

This chapter presents a discussion of the results, beginning with a brief restatement of findings, followed by a specific discussion of the structural equation model. The chapter concludes with the strengths and limitations of the study, followed by implications for practice and directions for future research.

Primary Purpose and Findings

The purpose of this study was to test a conceptual model of communication, uncertainty and emotional well-being in a population of older breast cancer survivors. Guided by Mishel's theory of Uncertainty in Illness (1988) a conceptual model was developed from the literature. Previous empirical findings suggested the addition of two additional paths, between the stimuli frame and the dependent variable of emotional well-being, and between structure providers and emotional well-being.

Using structural equation modeling, this model was tested with a sample of 203 Caucasian and African American women over age 50 who had not experienced recurrence and were 5-9 years post original diagnosis and treatment. Only manifest variables were tested to facilitate ease in interpretation of interaction terms. Major findings supported all but one of the originally conceptualized links between variables and supported Mishel's theory of Uncertainty In Illness (1988a). There was no support found for the link between structure providers (operationalized as education and 5 measures of communication) and the stimuli frame (operationalized as symptom number and bother). Further, the anticipated moderating effects of age and ethnicity were not supported. Ethnicity had no significant relationship with any variable and was dropped from the reduced alternative model. However, age had a direct inverse association with the stimuli frame, and an indirect inverse association with uncertainty, mood state and troublesome thoughts of recurrence. Findings showed that as age increases, symptom bother as well as the corresponding uncertainty, adverse mood state and thoughts of recurrence, decrease (Figure 5.1). All other originally proposed conceptual linkages were supported.

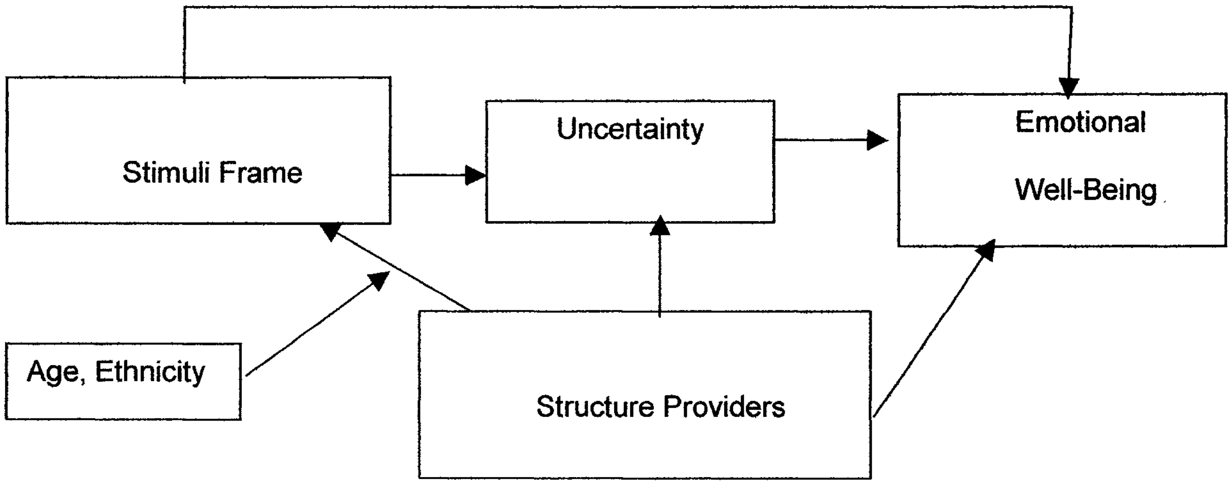
The Structural Equation Model

The influence of age and ethnicity

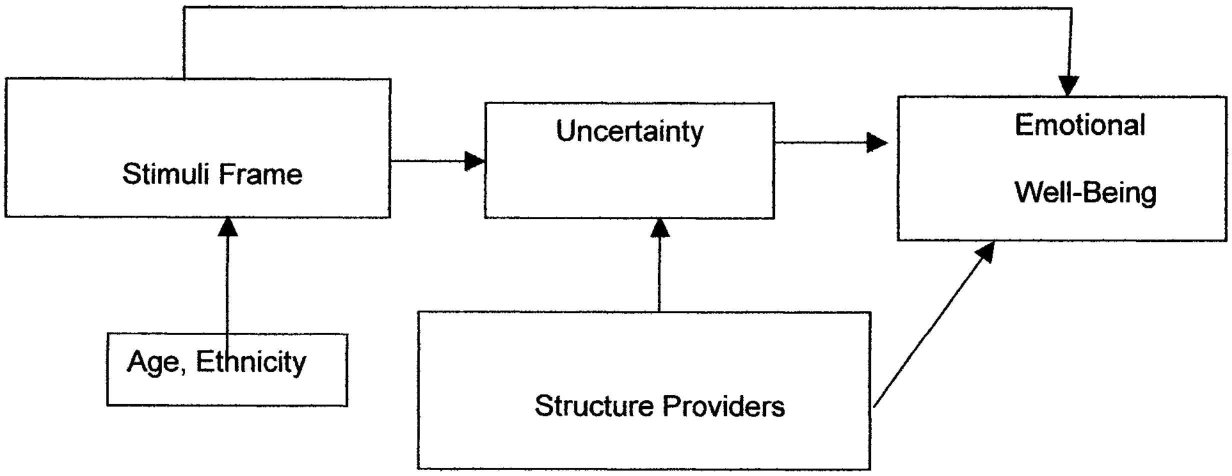
The original conceptual model was developed from empirical literature on older breast cancer survivors, with variable direction and position guided by Mishel's theory of Uncertainty in Illness. Empirical research suggested that age would moderate the relationship between a woman's symptoms and the communication process during decision-making, despite the fact that age is not a variable or concept in Uncertainty in Illness theory (Comstock et al., 1982; Crooks, 2001; Krupat et al., 1999). This path was not supported. However, age was found to have a significant direct effect on symptom bother accounting for 30% of the variance, suggesting that as age increases, symptom bother decreases. Further, age had significant indirect effects on uncertainty (11% of the variance), mood state (10% of the variance) and the amount of troublesome thoughts of recurrence (12% of the variance) as previously summarized in Table 4.21. Thus, age was highly influential in explaining symptom bother, uncertainty, and emotional well-being for this sample of older breast cancer survivors. It is possible that age will eventually be discovered to be a influential moderator of the relationship between the stimuli frame, uncertainty, and other outcomes in suggesting modification of Uncertainty in Illness theory.

Figure 5.1. Conceptual Model: Original versus Alternative supported pathways.

Original Model



Alternative Model



To assist in explaining this finding, age was examined for distribution. As previously discussed, all women were over age 50 with representation through age 96, yet within this range there was a higher percentage of women closer to age 50 than to age 90. Forty seven percent of respondents were between 50 and 60 years. These younger women were also the most likely to be employed and either married or living with a partner for more than 6 months.

The inclusion criteria of 50 years or older was originally chosen since this is the average age of menopause. Additionally, although it can be assumed that the majority of women age 50-60 would have completed menopause this is still a fairly recent change and further, these women may not have experienced a large number of other age related complaints such as arthritis as compared to those over age 60. Examining comorbidity data, findings showed that only 9% of this sample had no additional reported health problems. However, 65% of women reported managing between one and five additional illnesses. The number of other reported illness was modestly correlated with both age (.15 $p \leq .05$) and employment status (.21 $p \leq .05$).

Explanations for the large influence of age in this model may be that older women are more tolerant of their symptoms related to original breast cancer treatment than younger women, due to the aging process, and may be more familiar with discomforts due to other co-morbid conditions such as arthritis. Further, some complaints such as fatigue may not impact the lifestyle of an older woman who is more sedentary as compared to a younger woman who may still be employed or physically active, although this can not always be assumed to be true. In addition, menopause and associated symptoms such as trouble thinking, hot flashes, and weight gain, may be ambiguous and indistinct from those related to the side effects from breast cancer treatment. These symptoms may become more distinct and therefore understandable as a woman ages and menopause is completed, reducing uncertainty, adverse mood state and troublesome thoughts of recurrence.

Using Uncertainty in Illness Theory to assist in explaining this finding, it may be that as a woman ages, a cognitive schema develops related to aging. This schema may reflect an acceptance of existing symptoms, suggesting that more symptoms, and the associated bother, are to be expected, therefore older women experience less uncertainty, adverse mood state, and troublesome thoughts of recurrence due to greater predictability and understanding of their symptoms. However, in women closer to age 50, a cognitive schema of age related changes may not be relevant yet, causing these women to experience uncertainty about whether new symptoms represent a recurrence of their breast cancer, age related changes, or changes due to other illnesses. They do not know the meaning of their symptoms, therefore they are uncertain and cannot predict, identify, or attribute meaning to their symptoms. Supporting this theoretical explanation, Figures 5.2 and 5.3 demonstrate the effect of increasing age on symptom bother and troublesome thoughts of recurrence in this sample.

Previous research also supports current age related findings of lower uncertainty, symptom bother, less distress, and fewer thoughts of recurrence. Budin (1998) found a similar relationship between age and symptom distress in a study of 101 women age 28-80. She suggested that older women may be able to place their current discomforts within the context of their life experience and therefore are more accepting of their current discomforts. Another explanation suggested by Budin (1998) is that women perceive illness as an age related norm, therefore they are less distressed by the occurrence of illness than younger women. These explanations are similar to Uncertainty in Illness Theory's explanation of the development of a cognitive schema that allows prediction and understanding of symptoms and events, resulting in less uncertainty and correspondingly less adverse mood state.

Summarizing the effects of age, it appears that the placement of age as a moderator of communication with providers about experienced symptoms was incorrect. Rather, it appears that age has a strong impact as an independent variable facilitating the development of a cognitive schema that reduces uncertainty as well as the accompanying levels of mood distress and thoughts of recurrence.

Surprisingly, there was no relationship found between structure provider communication variables, and age. One explanation for the lack of support for a moderating effect of age on the relationship between communication variables and symptom number and bother may be found in the work of Turk-Charles (1997), who found that older women consult more non-medical sources of information than younger women. Similarly, Luker (1996) found that as time from diagnosis increased, fewer professional sources of information were consulted, rather women received more information from various media sources, suggesting that women may feel that healthcare providers are not the best source of information regarding symptom management. Rather than suggesting an inverse relationship with advancing age, it seems that the variable influencing patient-provider communication is time from diagnosis.

These findings, along with literature describing the fear of being perceived as ungrateful as a rationale for not mentioning symptoms to providers (Leigh, 1992), help explain why age did not moderate the relationships between measures of communication and measures of symptom bother for older long-term breast cancer survivors. It may be that older women in this study are simply not seeking medical opinion as frequently as younger women, due to their stage of survival or advancing age and the formation of a cognitive schema, allowing more symptoms to be understood and thus perceived as non threatening.

Figure 5.2 Influence of age on the reported amount of symptom bother by decade.

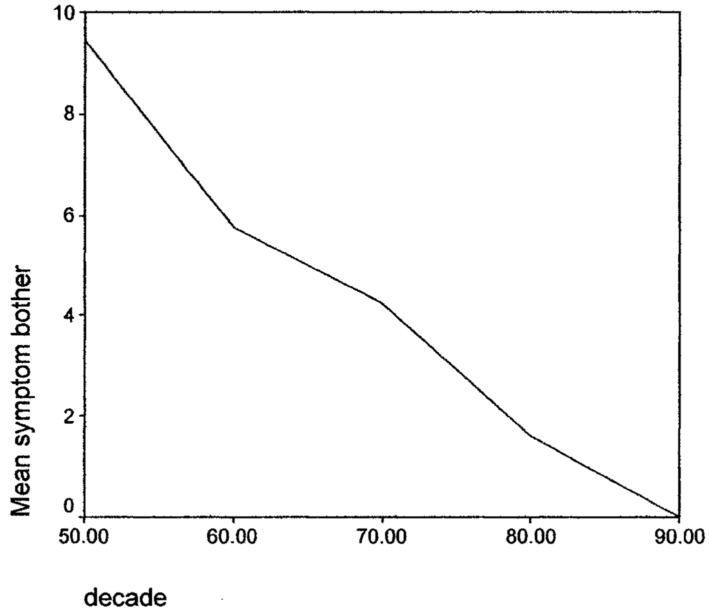
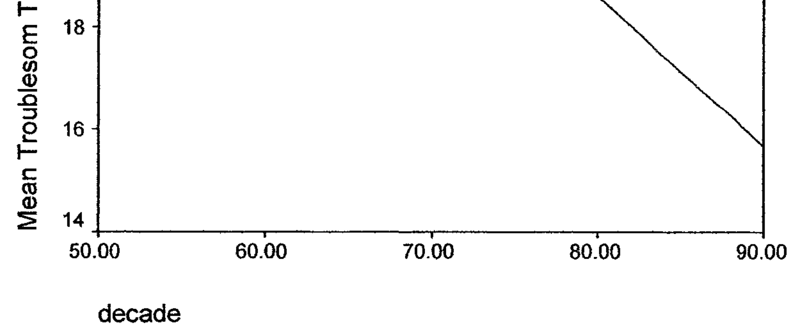


Figure 5.3. Influence of age on total troublesome thoughts of recurrence.



Another explanation may be that communication patterns and issues are different for stable and/or chronic illness as opposed to acute illness states. To date, much of the research regarding patient-provider communication surrounds the acute illness period, initial treatment decision-making, or active decision-making periods such as those at the end of life (Helmes, Bowen, & Bengel, 2002; Krupat et al., 1999; Makoul, Arntson, & Schofield, 1995; Roter & Hall, 1992; Roter, Larson, Fischer, Arnold, & Tulsky, 2000; Street, 1991; Wissow et al., 1998).

Ethnicity.

Recently, there has been much attention paid to the lack of research involving African American subjects, including observations of the lack of knowledge of the issues facing African American breast cancer survivors (Aziz & Rowland, 2002; Moore, 2001). While it is true that the issues and concerns of African American breast cancer patients are largely unknown due to samples that are predominantly Caucasian, findings from the present study suggest that ethnicity itself does not cause a difference when addressing issues faced by breast cancer survivors.

Ethnicity was originally conceptualized as a moderator of the relationships between measures of communication and measures of symptom number and bother. Initially, all measures were analyzed for reliability by ethnicity, as previously presented in Table 4.5, and did not display great variation by ethnicity. Additionally, ethnicity was independently analyzed for its influence on all endogenous variables. Findings showed that ethnicity was not influential, directly or indirectly, as a moderator of any endogenous variable.

To confirm this finding, and find possible reasons for the lack of influence of ethnicity, demographic variables as well as measures of symptom number and bother were assessed. Tables 5.1 and 5.2 demonstrate a lack of difference in symptom bother and symptom number due to ethnicity (symptom bother F= .003, df 1, *p*= .954; symptom number F= .770, df 1, *p*= .381). This is supported by other work demonstrating the overall symptom burden in breast cancer survivors irrespective of ethnicity (Gil et al., 2002; Mast, 1998a; Bower et al., 2000; Northouse et al., 1999; O'Hare et al., 1993; Paci et al., 1996; Hull, 2000).

Based on these assessments and the fact that ethnicity was not retained in the final model as an influential variable, ethnicity has not been discussed at length in this chapter. However, upon reflection, the fact that issues were seen to be universal to older breast cancer survivors and not influenced by ethnicity is in itself an important finding. Further, there was initial evidence of a moderating effect of ethnicity on education. Since this interaction was eliminated late in the model reduction process, it is possible that with increased power it may have remained significant.

Table 5.1 Symptom Bother reported for the total sample and by ethnicity.

Symptom	Total Sample N=203	%	Caucasian N=130	%	African American N=73	%
weight gain	16	7.9	8	6.2	8	11.0
fatigue	9	4.4	5	3.8	4	5.5
stiff arm	7	3.4	4	3.1	3	4.1
pain	6	3.0	2	1.5	4	6.7
trouble thinking	6	3.0	2	1.5	4	5.5
arm weakness	5	2.5	2	1.5	3	4.1
appearance	5	2.5	1	0.8	4	5.5
numb	4	2.0	2	1.5	2	2.7
hard dry skin	4	2.0	2	1.5	2	2.7
sensitive skin	2	1.0	2	1.5	0	0
arm swelling	2	1.0	2	1.5	0	0
limited shoulder	2	1.0	2	1.5	0	0
hand swelling	2	1.0	1	0.8	1	1.4
tender skin	1	0.5	1	0.8	0	0
change in scar	0	0	0	0	0	0

Table 5.2. Symptom Number reported by ethnicity.

Symptom	Total Sample N=203	%	Caucasian N=130	%	African American N=73	%
numb	127	62.6	91	70	36	49.3
sensitive skin	89	43.8	66	50.8	23	31.5
tender skin	88	43.3	68	52.3	20	27.4
fatigue	82	40.4	51	39.2	31	42.5
arm weakness	80	39.4	52	40.0	28	38.4
stiff arm	78	38.4	44	33.8	34	46.6
weight gain	63	31.0	40	30.8	23	31.5
pain	58	28.6	38	29.0	20	27.4
limited shoulder	53	26.1	35	26.9	18	24.7
arm swelling	48	23.6	29	22.3	19	26.0
hard dry skin	48	23.6	33	25.4	15	20.5
hand swelling	45	22.2	13	19.4	21	28.8
trouble thinking	44	21.7	26	20.0	18	24.7
appearance	29	14.3	38	29.2	8	11.0
change in scar	29	12.6	21	16.2	6	10.0

The finding that ethnicity is not related to psychosocial outcomes has been reported elsewhere. Ashing-Giwa (1999) found that differences in health related quality of life were not due to ethnicity, but rather to socio-economic status and the level of endured life-burden (operationalized by Ashing-Giwa as a composite of illness burden, social support, and life stressors) in a sample of 117 African American and 161 Caucasian long-term breast cancer survivors. Thus, similar socio-economic status may explain similarities among these women in addition to a lack of difference in issues by ethnicity. Similar to current findings, ethnicity was not retained in the final regression model by Ashing-Giwa as a significant independent variable. Additional work by Rodrigue (1997) also found no differences due to ethnicity in the psychological adjustment of African American and Caucasian cancer survivors.

Research shows that breast cancer patients in general have difficulty in obtaining information (Carter, 1997; Girgis, Boyes, Sanson-Fisher, & Burrows, 2000; Gray et al., 1998; Suominen, 1992). Further, research shows that the length of the medical interview increases significantly with age for men but not for women (Mann et al., 2001). The lack of significant ethnicity based communication findings in this sample may be due more to female gender than differences in ethnicity, further explaining the lack of significance of ethnicity in the alternative reduced model. Thus, it is possible the effects of gender are stronger than the effects of ethnicity for older breast cancer survivors as they try to obtain information from providers.

Another explanation may be that racial difference are present closer to diagnosis and treatment, but due to the mortality of women with advanced disease, women 5 or more years from diagnosis are more similar in education and socio-economic status, reflecting early detection and treatment of stage 1 or 2 rather than later detection of more progressive disease.

Some research has demonstrated racial differences in outcomes such as social functioning among women with breast cancer (Bourjolly, Kerson, & Nuamah, 1999), and health related quality of life as well as tumor stage at diagnosis in men with prostate cancer (Lubeck et al., 2001). Thus from the empirical research found it would seem that racial differences may be diagnosis and /or outcome specific. With respect to psychosocial outcomes in women with breast cancer, study findings are consistent with previous research showing that ethnicity was not influential. It is unknown whether this is true in samples with other diagnoses such as prostate cancer or for research with other outcome measures.

In summary, because ethnicity did not attain significance in the structural equation model, and therefore not retained in the final alternative model, analysis was not conducted by ethnicity, except for descriptive statistics. However, it is important to note an absence of findings due to ethnicity when assessing the issues and outcomes important to breast cancer survivors.

The relationships between the Stimuli Frame, Uncertainty, and Emotional Well-being

Symptom number and bother.

Much of the current literature on breast cancer survivors has focused on the presence and frequency of experienced symptoms. It has been well established that breast cancer survivors have a multitude of symptoms they are managing on a daily basis (Ferrans, 1994). Findings from this study showed that 43% of women experienced up to three symptoms and 78% experienced up to seven symptoms. The mean number of experienced symptoms was 5. Strikingly, only 12% of women reported experiencing no symptoms indicating that symptoms remain prevalent for the vast majority of women at 5 or more years post original diagnosis and treatment.

Examining the empirically suggested path from the stimuli frame to emotional well-being, findings from previous research support the relationship of increased symptom bother and adverse emotional well-being (Budin, 1998; Longman et al., 1999). Using the total score of the Symptom Distress Scale, rather than the subscale of bother, Budin (1998) found that symptom distress was the best predictor of psychological adjustment in newly treated breast cancer patients [mean age 53 years]. When symptoms created a higher burden, this in turn created more disruption of daily activities and women subsequently appraised their illness as more stressful. Budin (1998) concluded that when symptoms are assessed by healthcare providers, increased attention should be given to those symptoms that are appraised as particularly distressing since they may contribute to adverse emotional adjustment to breast cancer. Current findings support this conclusion.

Similarly, previous research among cancer patients in general has found that distressing physical symptoms are associated with emotional symptoms such as anxiety, as well as issues of inadequacy and self-esteem (Loescher et al., 1990; Mast, 1998b). Thus, findings from previous research as well as the current study add to a growing body of literature suggesting the influence of the stimuli frame (symptoms) on the emotional well-being of older breast cancer survivors. Using Uncertainty in Illness Theory to explain this influence, it would seem that the inability to attribute meaning to new or worsening symptoms and the associated ambiguity of these symptoms creates uncertainty, which is then cognitively interpreted as the possibility of recurrence and/or is the cause of adverse mood state. Future research will be needed to test this interpretation.

Uncertainty in Illness Theory suggests that as the ambiguity of symptoms is reduced, the associated uncertainty, and emotions such as anxiety, are also reduced. Meaning can be assigned to symptoms and further, a distinction may be able to be made between what a woman believes is normal and what she believes is abnormal. When a symptom occurs that is new and does not fit into her cognitive schema, then uncertainty, distress, and fears of recurrence resurface. Additionally, events such as a reminder of previous treatment created by a visit with a provider may also cause fleeting thoughts of recurrence, yet are able to be cognitively placed within the past. However, when new and ambiguous symptoms occur, or an exacerbation of a previously stable symptom occurs, the corresponding uncertainty may generate more pervasive fears of recurrence.

Although current findings support the well-documented prevalence of symptoms in this population, symptom number was not retained as a significant variable in the structural equation model as a predictor of uncertainty and emotional well-being.

Rather, it was the degree of bother of experienced symptoms that was found to predict uncertainty, mood state, and troublesome thoughts of recurrence. Symptom bother directly accounted for 39% of the variance in uncertainty, and further, when both direct and indirect paths through uncertainty are considered, symptom bother predicted 33% of the variance in mood state and 42% of the variance in troublesome thoughts of recurrence. However, considering the high correlation between symptom number and symptom bother, these variables can be considered redundant and would be expected to behave similarly as measures of the same concept of symptom pattern and experience. Both symptom number and bother were moderately correlated with uncertainty, mood state and troublesome thoughts of recurrence, however in this sample, correlations were 3-6% higher overall for symptom bother than for symptom number as previously described in Table 4.19.

Fatigue is a symptom often reported to cause a significant amount of bother for breast cancer survivors. Current findings showed that while 40% of the total sample experienced fatigue, fatigue was the second most bothersome symptom, second only to weight gain, perhaps due to the degree of lifestyle disruption these symptoms create. Comparing Tables 5.1 and 5.2 it becomes obvious that the most frequent symptoms are not the most bothersome symptoms. In fact, the most bothersome symptom of weight gain was the seventh most prevalent symptom, reported by 31% of subjects.

Thus, while measures of symptom number and symptom bother are highly correlated (to be bothered by a symptom the symptom must be present), they are not identical. These findings suggest that both number and bother should be measured when assessing the overall impact of symptoms. These variables can also be assumed to act similarly if either measure is used independently, due to their very high correlation and therefore their redundancy.

While measurements of symptom number are more prevalent in the literature, research investigating the impact of symptoms including bother, has been conducted. Mast (1998a) found that symptom distress as an indicator of bother was positively associated with uncertainty in older breast cancer survivors, using the same instrument as in this research, a modified version of the symptom distress scale (McCorkle & Young, 1978). Similar to findings from the current study, Mast (1998a) found that fatigue was the most burdensome symptom in women that were 5 months post treatment. Other work has also found fatigue to be a highly bothersome symptom (Longman, Braden, & Mishel, 1996).

Qualitative findings by Ohlen (2002) suggest that managing physical changes does not mean an absence of symptoms, but rather managing bothersome symptoms while understanding that the body is the primary interface with the environment. When one is constantly reminded of an altered self, enduring these symptoms becomes more difficult and will impact the ability to reconcile oneself to an altered body and life "as it has become" (Ohlen et al., 2002, pg 321). For example, symptoms such as the appearance of scars, weight gain necessitating changes in wardrobe, reduced energy levels, and decreased use of an arm or hand may require altering of schedules and activities. These symptoms require adjustments to lifestyle that were not required before diagnosis and may be more bothersome for some women than others until they are incorporated into a cognitive schema or become integrated into a new sense of self. For example, a mild degree of hand swelling might not bother most women, but could cause great distress for an accomplished pianist. Similarly, lack of energy might not distress a woman accustomed to a sedentary lifestyle, but might greatly affect a woman who was accustomed to regular physical activity. Thus, constant reminders of breast cancer may cause increased uncertainty, distress, and troublesome thoughts of recurrence due to an inability to understand their significance or an inability to integrate these chronic physical changes into a woman's current life style. Further, attention is constantly focused on the previous event of breast cancer due to the need to adjust daily activities, as well as alter ones lifestyle to incorporate changes such as weight gain or fatigue, again creating uncertainty and troublesome thoughts of recurrence.

The uncertainty and ambiguity generated by these symptoms may create adverse mood state and fears of recurrence. Current findings show that uncertainty was responsible for 27% of the variance in troublesome thoughts of recurrence and 16% of the variance in mood state. Taken together, uncertainty was responsible for 43% of the variance in a woman's emotional well-being. Previous research with breast cancer patients and survivors provides support for these findings demonstrating that increased uncertainty is directly related to adverse emotional well-being (Braden et al., 1995; Deane & Degner, 1998; Gil et al., 2002; Mast, 1998b; Northouse et al., 1995; Silberfarb, 1984; Wong & Bramwell, 1992).

When symptoms can be managed or are integrated into a new routine, a new cognitive schema has been developed, resulting in less bother and disruption in mood state, due to the fact that they are now incorporated into a new way of being; a new way of interfacing with the world. Nelson (1996) described this as "learning new ways of being in the world" (page 67) in a qualitative study of women 2-6 years post original breast cancer treatment. Thus, the new self becomes familiar and the perception of an altered body and the accompanying uncertainty, adverse mood state, and fears of recurrence are lessened.

Viewed in this perspective, current findings are theoretically consistent with Uncertainty in Illness Theory in that bothersome symptoms serve as constant reminders of an altered self, and further, the need to develop new daily routines that are unfamiliar and unpredictable creates uncertainty. When new ways of interfacing with the environment become routine, predictable, less ambiguous, and are integrated into a cognitive schema, then uncertainty, adverse mood state, and troublesome thoughts of recurrence are reduced. The body image and accompanying changes due to surgery or treatment are more understandable, and do not seem "altered" in the sense of how one is able to interface with the environment.

Troublesome thoughts of recurrence.

When assessing the emotional well-being of breast cancer survivors, previous research supports the finding of a relative lack of a distressed mood state yet persistent fears of recurrence (Dow et al., 1996). Additionally, many studies have found that fears of recurrence are prevalent, but not constant (Ferrell et al., 1998). Some research has found that up to 89% of breast cancer survivors admit to fears of recurrence, yet report a small amount of mood disturbance (Polinsky, 1994). It may be that the ambiguity associated with symptoms lessens over time, yet reminders of previous disease remain.

Current findings show that 100% of this sample admitted to experiencing at least one negative thought of recurrence, yet consistent with other findings (Cameron & Horsburgh, 1998; Mast, 1998b), did not experience significant mood disturbance. The most frequent negative thought of recurrence, the doctor might be wrong, was reported by 63% of respondents, yet none admitted to experiencing this thought all the time, in fact, only 4% experienced this thought often while 59% experienced this negative thought of recurrence seldom to sometimes. Thus, this study supports other literature discussing the persistent but occasional nature of fears of recurrence, as well as the low level of acute mood disturbance in breast cancer survivors.

Qualitative work by Nelson (1996) supports these findings, also suggesting even though uncertainty may decrease over time, fears of recurrence remain. This study interviewed women who were 2-6 years post treatment for their perceptions of uncertainty. Emerging themes suggested that uncertainty decreased over time as women became further from diagnosis and treatment, but was occasionally "punctuated" with "sharp" reminders of an uncertain future by events such as entering the hospital where original treatment was obtained. Anxiety was described as a vague nonspecific sensation that women eventually learned to ignore using distraction or avoidance of specific contextual threats, but the fear of recurrence, although not always present, was unpredictable and acute. Additional qualitative work by Vickberg (2001a) further demonstrates the persistent, but not constant, nature of the uncertainty and corresponding fear of recurrence in a sample of 16 breast cancer survivors 1-5 years post treatment.

In summary, current findings and previous research support the inclusion of two conceptual indicators of emotional well-being (troublesome thoughts of recurrence and mood state). Further, the comparatively low correlation between these variables (0.27 found in Table 4.19), and the fact that symptom bother predicted both mood state as well as troublesome thoughts of recurrence, suggests that these two measures are related but separate indicators of emotional well-being. Mood disturbance and troublesome thoughts of recurrence are both a result of the uncertainty and corresponding inability to understand and predict the outcome of symptoms and an inability to integrate new or worsening symptoms into a cognitive schema. Thus, both adverse mood state and fears of recurrence may result from the physical manifestations, lifestyle adjustments, and the bother attributed to physical symptoms.

Summary of the Relationships between the Stimuli Frame, Uncertainty and Emotional Well-Being

The predicted relationships between the stimuli frame, uncertainty and emotional well-being were found to be consistent with Uncertainty in Illness Theory (Mishel & Braden, 1988; Mishel, 1988). Findings suggest that symptom bother is an overlooked but important indicator of the stimuli frame that is strongly associated with uncertainty, mood state, and troublesome thoughts of recurrence. These data suggest that symptoms are a major contributor to the uncertainty of breast cancer survivors.

The relationship between Structure Providers, Uncertainty, and Emotional Well-being

The relationship between education and uncertainty.

Consistent with Uncertainty in Illness theory, the path between structure providers and uncertainty was supported. However, the only structure provider variable related to uncertainty that attained significance was education. Theoretically, education is hypothesized to reduce uncertainty through greater experience and knowledge, thus making patients more able to understand their illness and treatment (Mishel, 1997).

This finding adds to the research findings on the inconsistent relationship between education and uncertainty. Research findings support this relationship in cardiac and in cancer patients (Christman et al., 1988; Mishel et al., 1984) and in breast cancer survivors (Hilton, 1994; Mast, 1998a; Wonghongkul et al., 2000). Other research refutes this finding in a variety of medical diagnoses (Mishel, 1984), newly treated breast cancer patients (Wong & Bramwell, 1992), and in colon cancer patients (Galloway & Graydon, 1996).

One explanation for these mixed findings may be that this particular relationship is moderated by time since diagnosis, a variable that was not operationalized in this study since all women were 5 – 9 years from diagnosis. As time goes on patients become more knowledgeable about all facets of their disease as well as learning how to manage treatment side effects, irrespective of formal education. Yet, general knowledge was not an operationalized variable in this study. Rather, current findings indicate that increased formal education is predictive of decreased uncertainty, and indirectly, improved mood state and fewer fears of recurrence.

In this sample, mean years of self reported education were 13, ranging from 2-21 years. However, 52% of the sample had 12 years of education (completion of high school) or more, thus this sample was fairly well educated. Only 12% had eight or less years of education reflecting an absence of the advanced formal instruction attained during high school. Therefore, it could be hypothesized that not only was this sample well educated, but that they possessed the education (resources) needed to obtain and understand the diagnosis and management of breast cancer.

Uncertainty in Illness Theory suggests that education provides the resources necessary to interpret, understand, and predict events. Therefore, a well-educated sample would be expected to have lower levels of uncertainty, as demonstrated by current findings. Education facilitates understanding of verbal explanations provided by healthcare providers, as well as understanding of the information provided in pamphlets and other written information sources that are often distributed to patients by providers as a supplement to verbal explanation. Understanding allows patients to predict a course of events. Symptoms can be predicted and become congruent with what was expected based on prior information, such as the experience of fatigue for many months following chemotherapy. Further, increased education may allow the survivor to differentiate between symptoms indicative of recurrence and those representing normal aging and / or other illnesses.

This ability to identify and understand the meaning of symptoms could be thought of as a continuum, less education would allow more symptoms to be confused with recurrence whereas more education would allow greater discrimination of symptoms that are understood, versus those that might indicate recurrence. Based on empirical findings, however, it can be seen that women even with high levels of education are unable to totally discriminate serious from benign symptoms (Leigh, 1992). As suggested by Uncertainty in Illness Theory, when symptoms can be understood and are congruent with what was expected, perhaps due to increased formal education, uncertainty is lessened as is anxiety and the fear that a particular symptom is indicative of recurrence.

Finally, education may be a proxy for literacy in some samples. Aziz (2002) suggests that providers may need to use different methods of communication based on educational preparation. Findings from my research suggest that increased education was associated with decreased uncertainty. Further, both African-American women and Caucasian women were comparatively well educated (mean education 12 and 13 years respectively), which would allow the use of multiple sources of information, regardless of ethnicity. My findings are consistent with Uncertainty in Illness Theory, suggesting that greater education permits greater understanding of events and experiences, providing more resources that assist patients to understand and frame their illness experience, thereby reducing uncertainty.

The relationship between communication and uncertainty.

Structure provider variables were operationalized as patient-provider communication and represent interaction with a credible authority. None of these communication variables were significantly related to uncertainty, and only the total amount of patient-provider communication was retained in the final model due to a relationship with troublesome thoughts of recurrence. This was surprising since a major mechanism for reducing uncertainty directly via a structure provider is the acquisition of information (Mishel & Braden, 1988). Moreover, the provision of information by a credible authority such as a healthcare provider is thought to be a major factor in reducing uncertainty by enhancing the familiarity and predictability of events and symptoms and providing meaning to illness events (Mishel, 1997).

Moreover, patient-provider communication difficulties are reported frequently in the literature, suggesting the importance of including this measure in the original model. Lerman (1993) reported 84% of breast cancer patients endorsed at least one communication problem with their providers. Lerman found that the most prevalent communication problem (reported by 50% of respondents) was difficulty in understanding information given to them by their provider. Similarly, Crooks (2001) found that information was presented without accompanying interpretation by healthcare providers creating a lack of understanding and associated uncertainty among older women with breast cancer.

One explanation for the finding that no communication variables predicted uncertainty in the final model is found in research by Leigh (1992), who showed that when older women with breast cancer seek the advice of their provider in an effort to distinguish between benign and serious symptoms, they are reluctant to mention their symptoms for fear of being perceived as critical or ungrateful. Other work by Johnson et al (1996) found that although 76% of women with newly diagnosed breast cancer had specific fears about their diagnosis, only half revealed these fears to their providers. It follows that unless patients are willing to discuss their concerns and are ready to obtain information from their providers, uncertainty will not be reduced by patient-provider communication. Data from the current study show that women reported doctors talked more to them than they talked to their doctors (Figure 5. 4).

Examining the means of individual items on the patient-provider communication scale, there is overall more dialogue from doctors and nurses to patients than from patients to doctors and nurses (Table 5.3). It is interesting to note that the amount patients tell doctors and nurses falls between “almost nothing (2)” to “a little (3)”, and the amount doctors and nurses tell patients falls between “a little (3)” and “a moderate amount (4)” suggesting that patients receive more information than they impart. Therefore, by extension, patients may be receiving information they either were not ready to hear or were not anticipating. However, these data do not describe *what* was just discussed, just *how much* discussion took place. Further study is needed to examine the content of discussions in order to answer the question of *why* more talk predicts more troublesome thoughts of recurrence. Conversely, it may be that a larger number of troublesome thoughts of recurrence triggers more talk between patient and provider. In summary, the lack of a relationship between uncertainty and patient-provider communication, coupled with the finding of a positive relationship between thoughts of recurrence and patient-provider communication, suggests a need for further exploration of the relationship between communication, uncertainty, and thoughts of recurrence.

Figure 5.4. The difference between what doctors tell patients, and what patients tell doctors.

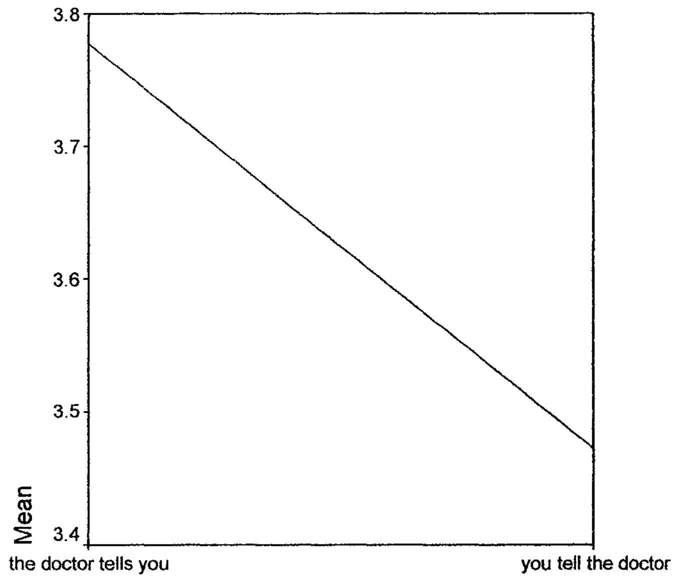


Table 5.3. Means of individual items on the Patient-provider Communication Scale

	Mean	Std. Deviation
how much doc tells how you are doing	3.78	1.12
how much nurses tell how you are doing	2.81	1.30
how much you tell doc problems	3.47	1.30
how much you tell nurses problems	2.79	1.32
how much you help decide your care	3.92	1.17

If some patients are unwilling or not ready to engage in dialogue with providers, the argument must now turn to individual characteristics and patient preferences. Descriptive findings from the Control Preferences scale show that over 40% of women were not able to attain their desired decision-making role with their provider. An analysis of the discrepancy between desired and attained roles showed that despite the fact that 60% of women achieved their desired decision-making role, there was an almost equal number of women who were forced to be more active or passive in decision-making than they had originally desired. These findings are similar to previous research using this instrument (Degner et al., 1997a; Tattersall, Butow, & Clayton, 2002). Other research has found even smaller percentages of patients achieve their desired role, as shown by Ramfelt (2000) who found only 44% achieved their desired decision-making role among newly diagnosed colorectal cancer patients.

It is unknown why the Control Preference Scale did not retain significance in the structural equation model. Possibly this instrument needs modification for uses with samples containing African-American women. Other reasons may be the inability of patients to accurately discriminate between the 5 choices, indeed several previous uses of this instrument have collapsed existing categories into three conceptual choices of active, collaborative, and passive decision-making role preference (Pyke-Grimm, Degner, Small, & Mueller, 1999; Ramfelt et al., 2000).

Finally, the fifth indicator of patient-provider communication, the Patient Perception of Involvement in Care Scale did not achieve significance. It is thought that this scale may have been a poor indicator of patient-provider communication, possibly not capturing the complexity of this process. Additionally the dichotomous nature of this scale may not encompass the variation among participation preferences for older breast cancer survivors, again, not reflecting the complexity of the process of patient-provider communication in terms of patient preferences. A notable lack of situational context in this scale may cause a respondent to be unable to provide a representative agree / disagree response to a statement such as: “I insisted on a particular kind of test or treatment for my symptoms.” Further, items such as this one require subjects to respond both to a kind of test as well as the type of treatment, which confuses concepts and possibly respondents.

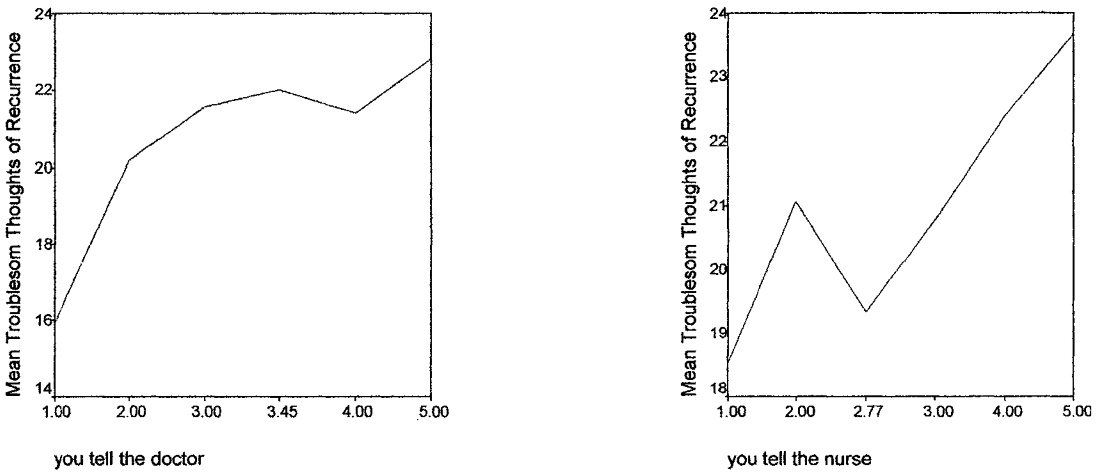
Communication and emotional well-being.

An empirically suggested path between structure providers and emotional well-being was added to the conceptual model based on literature suggesting that healthcare providers can directly affect emotional well-being (Rutter et al.,1996; Steptoe et al., 1991; Wineman et al., 1996). Current results show no relationship between patient-provider communication and mood state, similar to findings reported by Molleman (1984) regarding the relationship between communication measures and mood state. However, a significant relationship was found between patient-provider communication and troublesome thoughts of recurrence, accounting for 22% of the variance in troublesome thoughts of recurrence.

A graphic examination of individual items showed that each of the five items on the patient-provider communication scale had a positive relationship with the amount of troublesome thoughts of recurrence. As the total amount of communication increased, whether patients listened, spoke, or were helping to plan their treatment, so did the overall amount of troublesome thoughts. However, the only items that were significantly correlated with troublesome thoughts of recurrence were "you tell the doctor" (.27 $p \leq .01$) and "you tell the nurse" (.23 $p \leq .01$). Thus, it may be irrelevant that doctors spoke more than patients. Rather, as patients shared information about their symptoms, regardless of amount or bother, it seems to be the cognitive focusing on symptoms that predicts more troublesome thoughts of recurrence.

To assist in explaining the finding that increased patient-provider communication predicts increased troublesome thoughts of recurrence, three breast cancer survivors who were age 50 and older and were five or more years from original diagnosis without recurrence, were consulted. These three women were not part of the current research. All were known to me for longer than 4 years, and were willing to talk freely about their experiences. These women independently stated that providers often gave more information than they "wanted to hear."

Figure 5.5 Amount of communication between doctors, nurses, and patients.



Further, during yearly follow-up visits with their provider, all thought they were doing well, only to have the provider alert them to a symptom they had not attributed to their breast cancer, asking them to monitor it and return if it got "worse." Events they were asked to monitor included changes in skin texture and color, fatigue level, and changes in weight. This, in turn, caused the women I consulted to experience more uncertainty. None were overly anxious, but all admitted that their uncertainty and corresponding fear of recurrence was heightened by visits with their provider, possibly by focusing their attention on symptoms that they now cannot explain, and are ambiguous, as well as the cognitive attention and vigilance needed to "monitor" a symptom.

This explanation is consistent with the qualitative findings of Nelson (1996) who recounted that as breast cancer survivors found hope in the uncertainty of their illness experience, they also acknowledged the fragility of that hope. Women stated that hope could be “shattered, depending on what was said and how it was worded” (pg 64). When to much information was offered women became focused on the negative rather than the positive attributes of their disease trajectory. Conversely, too little information created feelings of anxiety and fear, which also changed hope to hopelessness. Nelson (1996) concluded by noting that women tried to regulate the information flow offered by providers as a way of maintaining their hopefulness during the uncertainty of the illness experience.

Findings from this study, and well as prior work by Nelson (1996) and Brashers (2000a) point to the importance of information management as a way of managing uncertainty, and reducing troublesome thoughts of recurrence. The idea of patients managing information as means of coping with uncertainty is explicated by Brashers (2000a), who offers a theory of information management developed with HIV patients. Brashers notes that the method of information management, such as seeking or avoiding information, may fluctuate depending on contextual factors such as newly available and promising treatments. In summary, providers who are not attendant to the wishes and information management desires of the patient may actually violate the ethical principal of doing no harm by increasing fears of recurrence, and potentially facilitating higher levels of uncertainty, depression, and troublesome thoughts of recurrence.

Summary of the Structural Equation Model

Results from this research show that age is a highly significant factor when predicting the emotional well-being of older breast cancer survivors. Supporting previous research, older women tended to have less symptom bother, and correspondingly less uncertainty, less mood disturbance, and fewer troublesome thoughts of recurrence. It may be as women age they develop a cognitive schema that allows them to predict and understand the meaning of their symptoms, resulting in less uncertainty and correspondingly improved emotional well-being. Symptoms become less ambiguous and better understood. The role of education may also provide women with the resources necessary to reduce the ambiguity of their symptoms, again resulting in less uncertainty and improved emotional well-being.

The results of communication findings are less clear. Results show that while patients reported that doctors spoke more than they did, it was the amount patients told doctors and nurses that was positively correlated with troublesome thoughts of recurrence. Possibly, it is the need to focus attention on symptoms as women relate their concerns to providers that facilitates troublesome thoughts of recurrence. Or, it may be that once a symptom is mentioned to a provider, this causes a more lengthy provider-offered discourse about that symptom and its implications than the woman desired or expected. Similarly, another explanation suggested by uncertainty management theory (Brashers et al., 2000a) is that women are not able to manage the information received from their doctors and nurses. Since patients reported that providers (doctors and nurses) told them more than they told their providers, it is possible that they received information that was unexpected, or unwanted. However, since the content of this discourse is unknown, and there was no relationship of communication with uncertainty, future research were needed to clarify the mechanism by which communication influences troublesome thoughts of recurrence.

Future Research

Findings from the current study suggest that the amount of bother a woman attributes to her symptoms may place her at risk for adverse emotional well-being, suggesting a need for greater attention to the experienced distress of symptoms reported by women. Symptoms that were discovered in my dissertation to cause women the most bother were, in descending order, weight gain, fatigue, pain, trouble thinking, and arm problems due to their original breast cancer treatment. These were not the most prevalent symptoms reported by these women. Because many of these symptoms are subjective and may not have clear physiological manifestations, treatment often consists of management rather than curative strategies, requiring discussion between patient and provider regarding expectations and goals of treatment.

Uncertainty in Illness Theory suggests that these symptoms may be difficult for women to interpret, understand, and manage, creating increased levels of uncertainty, adverse mood state and troublesome thoughts of recurrence. Further, the subjective nature of these symptoms may mean that providers are also unsure how to help women manage these symptoms, requiring increased dialogue with the patient as they attempt to develop a treatment plan to address reported symptoms. Knowing that uncertainty is an important concept in this population, research addressing uncertainty management from the communication perspective similar to research previously conducted among HIV/AIDS populations (Brashers et al., 2000a) is needed to improve understanding of the impact of patient-provider communication among older breast cancer survivors.

Findings supporting the prevalence of uncertainty due to the persistent nature of symptom bother, and the resultant adverse mood state and troublesome thoughts of recurrence were highly significant. Future research will investigate the long-term consequences of persistent or recurrent uncertainty, and the physiological impact of enduring this uncertainty for sustained periods of time. Measures that evaluate the physiological outcomes of these variables, such as cortisol, will enrich understanding of the issues affecting survivorship as well as the consequences of not addressing prolonged uncertainty resulting from late emerging side effects of treatment.

Thus, further research will need to continue to clarify the impact of symptoms on fear of recurrence and uncertainty, and in addition, explore the impact of enduring physical symptoms on outcomes such as physiological stress markers and eventually length of survival. Additionally, research exploring differences in patient-provider communication between women with a large number of enduring symptoms versus those with comparatively fewer symptoms, may help identify areas for intervention helping specific subgroups of survivors attain a level of quality of life that they find acceptable. Other areas of symptom impact not addressed in this research, such as self image and social interaction, may also be influenced by long-term physical symptoms. Finally, the ethical issues of ignoring or not addressing persistent uncertainty and enduring physical side effects in an ever growing population of older breast cancer survivors provides an impetus for understanding and addressing the needs of this vulnerable population.

Future areas of inquiry include the effects of treatment on the emotional well-being of breast cancer survivors. For example, do women who receive adjuvant therapies such as tamoxifen have different outcomes with respect to the uncertainty about recurrence? Additionally, the effects of differing primary treatments were investigated to establish their influence on uncertainty and emotional well being especially with respect to quality of life. For example, chemotherapy may have a strong influence on health related quality of life due to the common side effect of profound and persistent fatigue (Bower et al., 2000; Mast, 1998a; Woo, Dibble, Piper, Keating, & Weiss, 1998).

Findings from the present study show that over 40% of women were unable to achieve the decision-making role that they desired during negotiation of treatment for their symptoms. Although this finding was not a significant variable in the final structural equation model, in that it did not predict uncertainty or emotional well-being, it is worthy of note due to the fact that current communication practices of providers are not in tune with the desires of patients. Future research will address whether or not a discrepancy between a woman's desired versus attained role moderates the relationship between uncertainty and / or symptom pattern, and emotional well-being.

Additionally, the high level of discrepancy between desired versus attained decision-making roles in this sample raises the issue of whether providers are meeting the ethical responsibility of respecting the autonomy of their patients or still adhering to a paternalistic model of care-giving. Interestingly, just as many women desired to be more active as desired to be more passive, reflecting the need for providers to ascertain the desires of their patients as they attempt to provide beneficent care, rather than enforce "mandatory autonomy" by requiring women to make decisions they do not wish to make (Parascandola, Hawkins, & Danis, 2002).

Based upon empirical findings that continue to describe the frustration of women during the process of patient-provider communication and the importance of this issue to breast cancer survivors, future research is needed to explore facets of this complex process and address whether these communication difficulties contribute in turn, to higher uncertainty and reduced emotional well-being for these women. Further, studies to clarify the impact of communication on multiple outcomes will increase knowledge of how the process of patient-provider communication, and the ability to achieve ones desired role, affects the illness experience for these women.

Finally, there is a need to discern the impact of other socio-demographic factors such as age, education, and income on emotional well-being. Research is needed to investigate whether ethnicity has been previously used as a proxy for other socio-demographic characteristics. Exploring the relationships between these characteristics, patient-provider communication, and mood state may suggest whether there is an "at risk" woman between 50-60 years of age, with a high a degree of bother and level of uncertainty, and/or who is experiencing communication difficulties resulting in reduced emotional well-being. Increased understanding of the relationship of age on patient-provider communication and subsequent emotional well-being of breast cancer survivors who are experiencing higher than usual distress from their symptoms will allow the development of interventions that can be specifically targeted towards improving emotional well-being in this particularly vulnerable population.

Limitations

Limitations of this research must include the sample size. While power was adequate, the size of the sample was still marginal for Structural Equation Modeling techniques. Second, subjects were obtained from three separate studies for this secondary analysis. However, a between groups comparison of subjects, as well as examination of means and standard deviations across measures, showed that subjects were comparable across groups (Tables 4.2, 4.3). Significant differences between groups were found for women obtained from "Promoting self-help: Underserved women with breast cancer" (R01 CA 64706-02, PI: M. Mishel). These nine subjects were younger, attained a more active decision-making role, and on average, reported more patient-provider communication than the two other larger groups of respondents.

However, due to the small number of subjects, findings for this very small group are not as reliable as for the other groups with larger numbers of subjects.

A third limitation with respect to the sample was that there were twice as many Caucasian women as African American women, although results showed that ethnicity was not an influential variable as previously discussed in chapter four. African American women had a similar number of reported symptoms and associated bother, and additionally, psychometrics for measures were similar for Caucasian women and African American women. Thus, there is no reason to think data would differ with a larger percentage of African American subjects, although a balanced sample would better substantiate this argument.

An additional limitation was the learning curve reported by data collectors associated with the use of the Control Preferences Scale. Although data collectors were initially trained in the use and scoring of this instrument, follow-up phone calls were made, and follow-up training classes were held, it was not until data collection was approximately 1/3 completed that data collectors indicated comfort in administering this instrument. Should this tool be used again in the future a longer training period might prove beneficial, although it must be emphasized that results were consistent with other reported uses of this instrument (Degner et al., 1997a; Tattersall et al., 2002), thus there is no reason to think that data are inaccurate.

Strengths

A major strength of this research is that it was theoretically based, as recommended when using structural equation modeling. The use of Uncertainty in Illness theory (Mishel & Braden, 1988; Mishel, 1988) assisted in identifying the relevant variables for this population, selecting the order of the variables in the conceptual model, and in interpreting the results.

Other strengths include the inclusion of African-American women, albeit smaller than the number of Caucasian participants, assisting in identifying the issues and concerns particular to this understudied group of women. Further, the inclusion of African American allowed assessment of the reliability and validity of the Control Preferences scale for African American older breast cancer survivors. This was the first known use of this instrument among African American women. Additionally, all measures demonstrated high internal consistency in this sample. Further, variables predicted a large amount of the variance in the emotional well-being of older breast cancer survivors, furthering understanding the issues important to this growing population.

Finally, this study represents a beginning attempt to understand the complex process of patient-provider communication and how it influences uncertainty and emotional well-being while accounting for individual differences such as symptoms, education and age.

Implications for Practice

These findings raise some important issues and implications for practice. As nurses, our practice often focuses on the presence or absence of symptoms as an indication of well-being. Instead, it may be more important to ask women how much a symptom is affecting their daily lives and how much it bothers them. If a symptom is especially bothersome, assisting the patient to find individually appropriate management strategies may facilitate less uncertainty and correspondingly improve emotional well-being. Further, until the process of how communication impacts troublesome thoughts of recurrence is better understood, sensitivity to the manner and amount of patient-provider communication is necessary.

Providers have an ethical responsibility to respect patient autonomy, provide beneficent care, and maintain standards of care. Parascandola (2002) argues that beneficence is doing what is best for the patient and should be thought of as whatever will ultimately promote well-being, a broader concept than delivering the best medical care available. Addressing the ethical responsibilities of providers caring for breast cancer patients, Parascandola (2002) cites Mishel's Uncertainty in Illness theory (1988a), noting that uncertainty is prevalent in this population. This uncertainty often results in anxiety and depression for those deciding upon treatment as well as those coping with long-term side effects. He suggests this prevalence of uncertainty in breast cancer patients challenges clinicians to avoid "mandatory autonomy" [forcing the patient to make all decisions] and provide a more beneficent style of care where the patient's quality of life is considered and merged with the goal of providing appropriate standards of care (Parascandola et al., 2002). The provision of ethical and competent care requires open dialogue between patient and provider, to facilitate the decision-making style that is preferred by the patient, as well as providing her with the risks and benefits of executing her decision. The result is the provision of truly beneficent care by ensuring informed consent, then respecting autonomy.

Further support for this argument is found in the communication literature. Johnson (2002) suggests that the result of providers not honoring the wishes of patients that prefer to let their provider make decisions, forces them to turn to less credible and potentially less knowledgeable information sources such as the internet, friends and family. Thus, following the ethical argument, the autonomy of the patient is ignored, beneficent care is not provided, nor are standards of care necessarily maintained. Therefore, to meet ethical standards, providers must assess and adhere to the decision-making preference of the patient. This can only be accomplished by open discourse between patient and provider.

Conclusion

This research represents a beginning attempt to understand the complex process of patient-provider communication while accounting for individual characteristics such as age, ethnicity, and symptom pattern. Findings from this dissertation suggest that age, the amount of symptom bother, and uncertainty are influential in predicting the emotional well-being of breast cancer survivors. Ethnicity does not appear influential based on current findings. Additionally, the results of this study suggest a relationship between patient-provider communication and troublesome thoughts of recurrence. Future research testing conceptual models derived from theories of information management among survivors of diverse ethnicities and ages will continue to facilitate understanding of this complex process.

The ability to identify a profile of an "at risk" survivor will assist in the development of interventions to promote the best quality of life possible for these women. Potential areas identified from this research that are amenable to intervention include uncertainty management, symptom management, and the impact of patient-provider communication on the amount of troublesome thoughts of recurrence. Uncertainty can be potentially reduced through interventions that assess the sources of uncertainty and then teach methods to manage uncertainty. Symptom management can be addressed from both clinical and psychological perspectives. Finally, troublesome thoughts of recurrence represent cognitions not emotions, and therefore are amenable to change. Providers can be taught to assess the impact of information and how it relates to each woman's information desires and management style.

In conclusion, this research has begun to elucidate the multiple factors that contribute to emotional well-being, both independently and as a result of interactions with other factors, in older breast cancer survivors. It is clear that there are multiple intertwined factors responsible for positive outcomes in this population. Further efforts to continue to unravel this complex process will assist breast cancer survivors to attain the best possible quality of life.

Appendix A: Definitions of Terms

Cognitive Schema	A subjective interpretation of illness.
Credible Authority	The degree of trust and confidence patients have in health care providers.
Emotional Well-Being	An overall measure of emotional wellness composed of the cognitive component of thoughts of recurrence, and the emotional component of mood state.
Patient-Provider Communication	Conversation occurring between patients and providers during the medical interview.
Stimuli Frame	The form, composition, and structure of received stimuli. Made up of the symptom pattern, event familiarity, and event congruency (the expected vs experienced events). An antecedent of uncertainty.
Structure Providers	The resources available to assist in the interpretation of the stimuli frame. Composed of the patient's education, level of social support, and the presence of credible authorities.
Symptom Pattern	The degree to which symptoms present with sufficient consistency so as to perceived as having a pattern, enabling understanding of symptoms.
Uncertainty	Inability to structure meaning of illness related events. A cognitive state, which is neutral until appraised as a danger or opportunity.

Appendix B: Symptom Distress Scale

(only symptom number and symptom bother are used in this study)

INSTRUCTIONS: Each of the following describes treatment side-effects you may have from your breast cancer treatment. Read each one carefully. If you have had the side-effect now or within the past 6 months, let us know how SEVERE it is, how much it DISTRESSES or BOTHERS you, and if you are finding ways to MANAGE it, by circling the appropriate number. If you DO NOT HAVE the side-effect, make an "X" in the box marked DO NOT HAVE and go on to the next numbered question.

Do you have any of the following side-effects or problems from breast cancer treatment?

1. Swelling in my hand DO NOT HAVE ☐ Go on to question 2.
If you DO have swelling,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

2. Dryness or hardness of my skin
in the treated area DO NOT HAVE ☐ Go on to question 3.

If you DO have dryness or hardness of skin,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

3. Stiffness in my arm and shoulder DO NOT HAVE ☐ Go on to question 4.

If you DO have stiffness,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

Do you have any of the following side-effects or problems from breast cancer treatment?

4. Pain DO NOT HAVE ☐ Go on to question 5.
If you DO have pain,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4
Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

5. Fatigue DO NOT HAVE ☐ Go on to question 6.

If you DO have fatigue,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4
Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

6. Tender areas of skin in the treated areas or underarm

DO NOT HAVE ☐ Go on to question 7.
If you DO have tender areas of skin,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

Do you have any of the following side-effects or problems from breast cancer treatment?

7. Trouble thinking DO NOT HAVE ☐ Go on to question 8.
If you DO have trouble thinking,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

8. Appearance DO NOT HAVE ☐ Go on to question 9.
If you DO have a change in your appearance,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe
How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

9. Arm weakness DO NOT HAVE ☐ Go on to question 10.
If you DO have arm weakness,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

Do you have any of the following side-effects or problems from breast cancer treatment?

10. Arm swelling DO NOT HAVE ☐ Go on to question 11.
If you DO have arm swelling,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

11. Sensitive areas of skin in the
treated area or underarm DO NOT HAVE ☐ Go on to question 12.

If you DO have sensitive areas,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4
Not at all Very Much
Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

12. Weight gain DO NOT HAVE ☐ Go on to question 13.

If you DO have weight gain,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4

Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

Do you have any of the following side-effects or problems from breast cancer treatment?

13. Further changes in the appearance
of my surgery scar or other areas
of my treated breast DO NOT HAVE ☐ Go on to question 14.

If you DO have a change in appearance,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4
Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

14. Numb areas of skin in the
treated area or underarm DO NOT HAVE ☐ Go on to question 15.

If you DO have numbness,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4
Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

15. Limited motion in my shoulder on the side where I had breast cancer. DO NOT HAVE ☐

If you DO have limited motion,
How SEVERE is it usually? 1 2 3 4
Slight Very Severe

How much does it DISTRESS
or BOTHER you? 0 1 2 3 4
Not at all Very Much

Are you able to find ways
to MANAGE it? 1 2 3 4
Usually Never

Appendix C: MUIS-S

Women who were treated for breast cancer may feel unsure or uncertain about many things related to their present situation. These next questions will help us find out about the things you are unsure about or things you don't know or fully understand. Read each question and circle the one number that tells us how much you agree/disagree with each item <u>TODAY</u>.

	STRONGLY AGREE	AGREE	UNDECIDED	DISAGREE	STRONGLY DISAGREE
I don't know if anything is wrong with me.	5	4	3	2	1
I have a lot of questions without answers.	5	4	3	2	1
I don't know if my cancer will ever come back.	5	4	3	2	1
I don't know how bad my discomfort might be.	5	4	3	2	1
The explanations they give me about my treatment side-effects do not make sense to me.	5	4	3	2	1
The long-term effect of my treatment is clear to me.	1	2	3	4	5
It is unknown whether I will have long-term problems from my treatment.	5	4	3	2	1
I understand everything explained to me.	1	2	3	4	5
The doctors say things to me that are confusing.	5	4	3	2	1
The long-term effects of my treatment are too complex to figure out.	5	4	3	2	1
I don't know if the treatments or medications are still helping me.	5	4	3	2	1
Because I don't know if my condition will change, I cannot plan for the future.	5	4	3	2	1
My treatment side-effects keep changing. I have good and bad days.	5	4	3	2	1
I have been told different things about what my treatment side-effects mean.	5	4	3	2	1

	STRONGLY AGREE	AGREE	UNDECIDED	DISAGREE	STRONGLY DISAGREE
I do not know what is going to happen to me.	5	4	3	2	1
The results of my mammography are inconsistent from one year to the next.	5	4	3	2	1
The long-term benefit from the treatment is unknown.	5	4	3	2	1
I'm certain they will not find anything else wrong with me.	1	2	3	4	5
The treatment I received is known to be successful.	1	2	3	4	5
They have not given me specific information about my long-term health.	5	4	3	2	1
I know how serious my breast cancer was.	1	2	3	4	5
The doctors and nurses use words that I can understand.	1	2	3	4	5

Appendix D: Demographic Information

Please fill in the following information about yourself.

1. AGE: _____ **DATE OF BIRTH:** _____/_____/_____

Month Day Year

2. MARITAL STATUS (*CHECK ONE*):

_______ Married
_______ Living with partner more than 6 months
_______ Separated
_______ Divorced
_______ Widowed
_______ Never Married

3. EMPLOYMENT STATUS (*CHECK ONLY ONE*):

_______ On medical leave from P/T job
_______ On medical leave from F/T job
_______ Retired (not working)
_______ Retired but working part-time
_______ Homemaker
_______ Unemployed
_______ Full-time employment
_______ Part-time employment
_______ Other

4. EDUCATION

How many years of school have you completed? __________

5. CHILDREN

Do you have any children? Yes _______ No _______

6. WHO LIVES AT HOME WITH YOU? (*CHECK ALL THAT APPLY*)

_______ Live alone _______ Other family (relationship) _____________

_______ Husband/ Partner _______ Friend(s)

_______ Children (under 18) _______ Other

_______ Children (over 18)

7. WHERE WERE YOU BORN?

_______ North Carolina
_______ Elsewhere in U.S. (Name state) _______________________
_______ Other (please specify) _______________________________

8. HOW MANY YEARS HAVE YOU LIVED IN YOUR CURRENT COMMUNITY? ______

9. INCOME

What is your monthly family income after taxes (take-home pay) from all sources (job, pension, social security, veteran's benefits, etc.)?
_______ less than $500
_______ $500 - $1,000
_______ $1,001 - $2,000
_______ $2,001 - $4,000
_______ more than $4,000

How many people live on this family income (it provides at least half of their income)? ________________

10. INSURANCE COVERAGE (*CHECK ALL THAT APPLY*)

_______ Medicare

_______ Medicaid

_______ Other health insurance

_______ HMO

_______ Self-pay (No insurance, Medicare or Medicaid; paying bills out of pocket)

11. FAMILY HISTORY OF BREAST CANCER (*CHECK ALL THAT APPLY*)

Mother (1)	**Sister(s)** (2)	**Paternal Grandmother** (3)	**Maternal Grandmother** (4)	**Aunt(s)** (5)	**Niece(s)** (6)	**Cousin(s)** (7)	**Daughter** (8)	**None** (9)
_____	_____	_____	_____	_____	_____	_____	_____	___
_____	_____	_____	_____	_____	_____	_____	_____	___
BDMOTH HX	BDSISTH X	BDPGRAHX	BDMGRAHX	BDAUNT HX	BDNIECH X	BDCOUSH X	BDDAUGH X	BDNO NEHX

APPENDIX E: Patient Provider Communication Scale

For each question, look at all the choices and circle the one which best describes the way things are during a TYPICAL DOCTOR/CLINIC VISIT for breast cancer checkup.

1. During a typical visit, how much does the doctor usually talk to you about how you are doing since you were treated for breast cancer?
    - 5) a great deal
    - 4) a moderate amount
    - 3) a little
    - 2) almost none
    - 1) none at all
2. During a typical visit, how much do the nurses and other treatment staff usually talk to you about how you are doing since you were treated for breast cancer?
    - 5) a great deal
    - 4) a moderate amount
    - 3) a little
    - 2) almost none
    - 1) none at all
3. During a typical visit, how much do you tell the doctor about problems you might be having related to your past breast cancer treatment?
    - 5) a great deal
    - 4) a moderate amount
    - 3) a little
    - 2) almost nothing
    - 1) nothing at all
4. During a typical visit, how much do you usually tell the nurses and treatment staff about problems you might be having related to your past breast cancer treatment?
    - 5) a great deal
    - 4) a moderate amount
    - 3) a little
    - 2) almost nothing
    - 1) nothing at all
5. During a typical visit, how much do you help with decisions about your care?
    - 5) a great deal
    - 4) a moderate amount
    - 3) a little
    - 2) almost none
    - 1) none at all

APPENDIX F: Perception of Involvement in Care Scale

Instructions:
Now we would like to ask you to think about the last time you went to your doctor with a problem. Please answer the following questions about what happened during that visit.

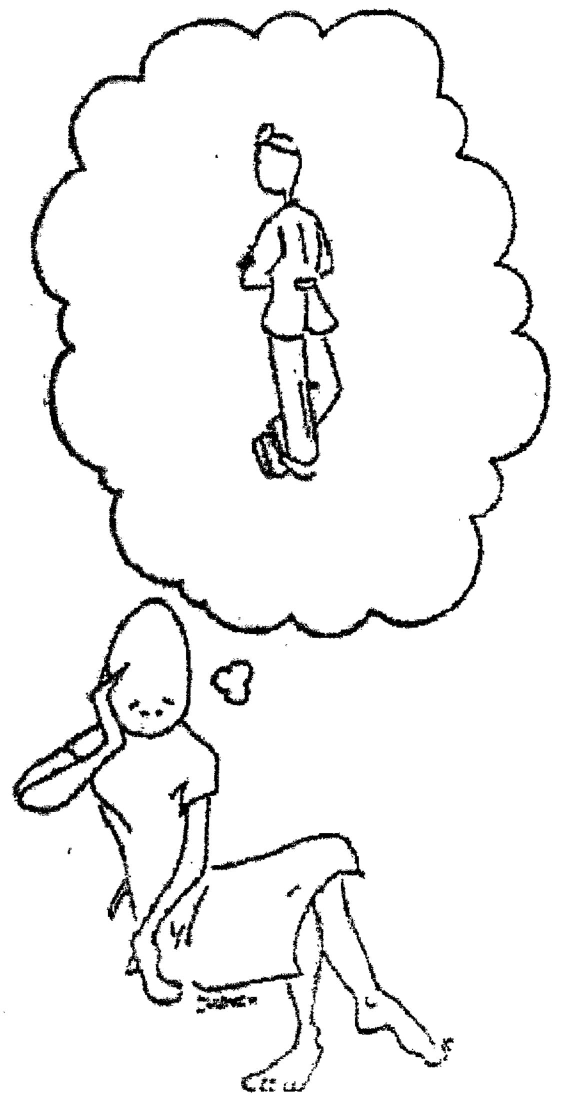
		Agree	Disagree	
1.	My doctor asked me whether I agree with his/her decisions.	☐	☐	____ PPIC1
2.	My doctor gave me a complete explanation for my symptoms or treatment.	☐	☐	____ PPIC2
3.	My doctor asked me what I believe is causing my symptoms.	☐	☐	____ PPIC3
4.	My doctors encouraged me to talk about personal concerns related to my symptoms.	☐	☐	____ PPIC4
5.	My doctor encouraged me to give my opinion about my treatment.	☐	☐	____ PPIC5
6.	I asked my doctor to explain the treatment or procedure to me in greater detail.	☐	☐	____ PPIC6
7.	I asked my doctor for recommendations about my symptoms.	☐	☐	____ PPIC7
8.	I went into great detail about my symptoms.	☐	☐	____ PPIC8
9.	I asked my doctor a lot of questions about my symptoms.	☐	☐	____ PPIC9

10.	I suggested a certain kind of treatment to my doctor.	☐	☐	PPIC10
		Agree	*Disagree*	
11.	I insisted on a particular kind of test or treatment for my symptoms.	☐	☐	PPIC11
12.	I expressed doubts about the tests or treatment that my doctor recommended.	☐	☐	PPIC12
13.	I gave my opinion (agreement or disagreement) about the types of test or treatment that my doctor ordered.	☐	☐	PPIC13

APPENDIX G: Control Preferences Scale

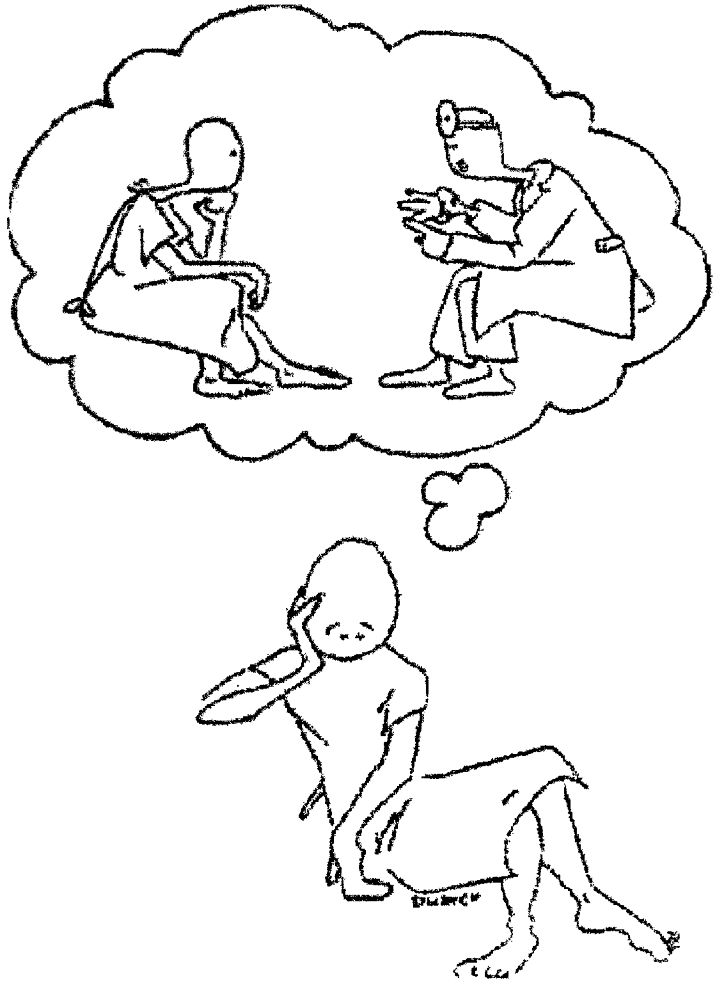
Card A

I prefer to make the final selection about the care I will receive.



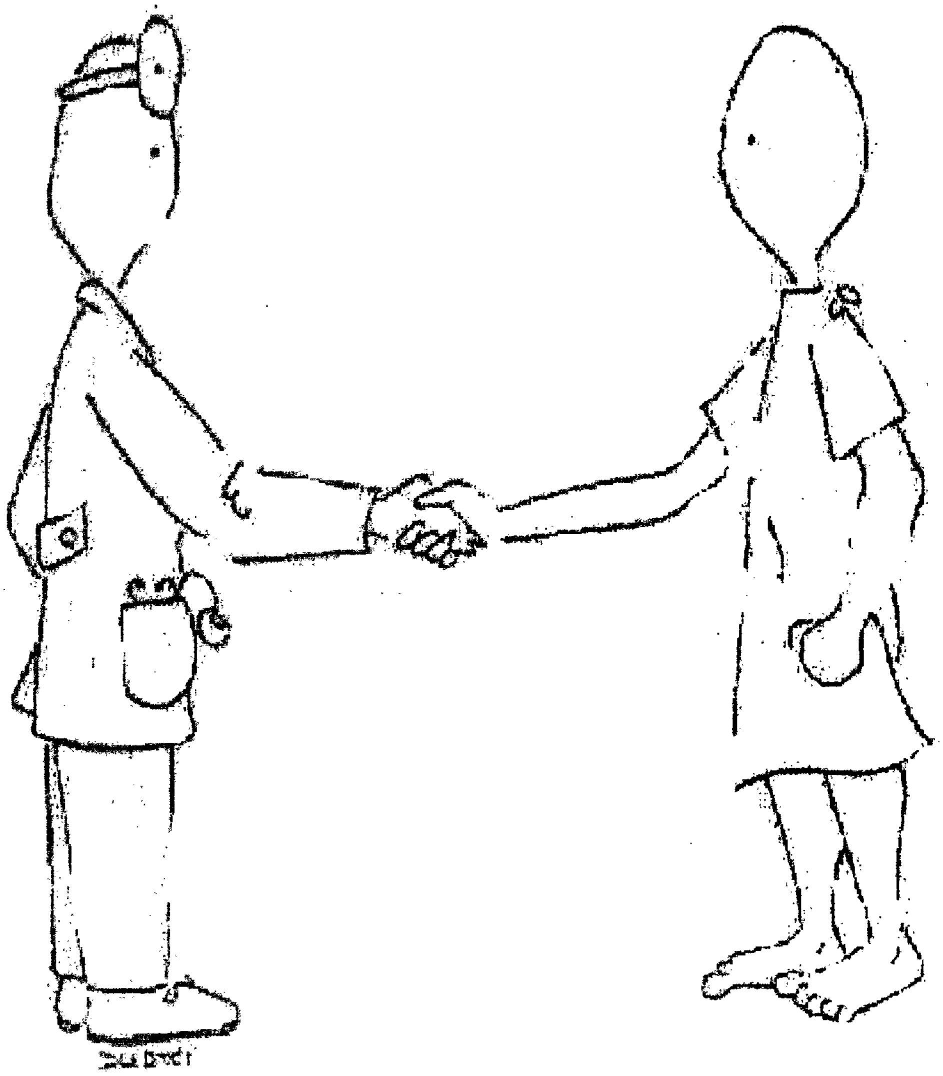
Control Preferences Scale Card B

I prefer to make the final selection about my care after seriously condisdering my doctor's opinion.



Control Preferences Scale Card C

I prefer that my doctor and I share resonsibility for deciding the type of care that's best for me.

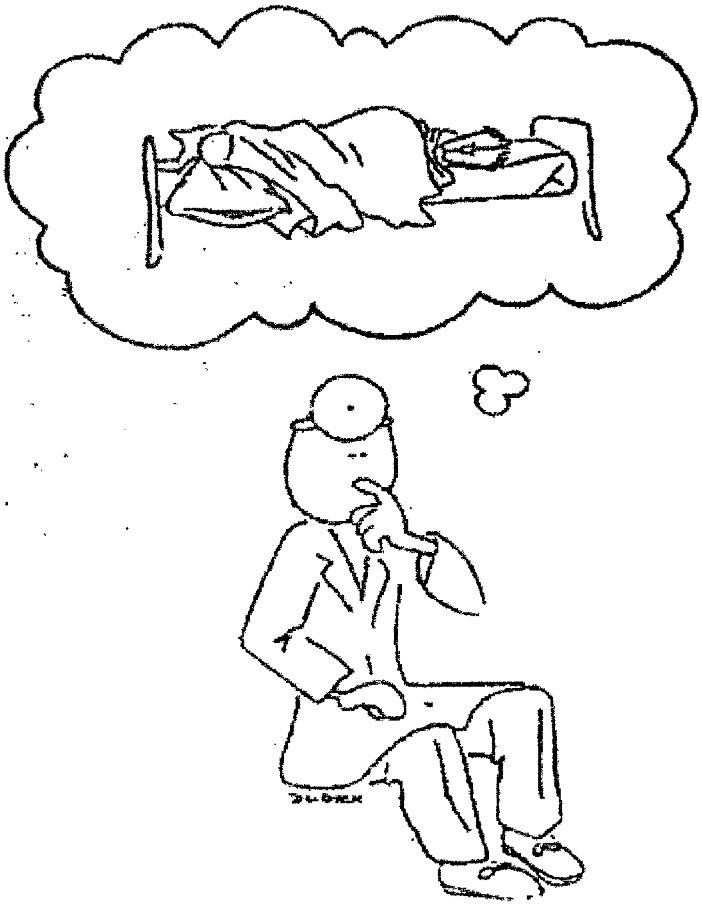


Control Preferences Scale Card D

I prefer that my doctor makes the final decision about my care, but seriously considers my opinion.

Control Preferences Scale Card E

I prefer to leave all decisions regarding my care to my doctor.



APPENDIX H: Scoring Sheet for The Control Preference Scale

1. What type of healthcare provider do you go to when you have problems that you think are due to your breast cancer or breast cancer treatment?
Data Collectors: Please check one box

General Family Doctor ☐ *(1)*
Oncologist ☐ (2)
Nurse Practitioner ☐ (3)
Other ________________ ☐ (4)

2. Role Preference
Data Collectors: Please check one box

☐	☐	☐	☐	☐	☐	☐	☐
A	B	B	B	C	C	C	C
B	A	C	C	B	D	D	D
C	C	A	D	D	B	B	E
D	D	D	A	A	A	E	B
E	E	E	E	E	E	A	A
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)

☐	☐	☐	☐
D	D	E	___
C	E	D	___
E	C	C	___
B	B	B	___
A	A	A	___
(9)	(10)	(11)	(12)

CPS_ T3_____

3. *What card best illustrates how decisions are actually made?* ☐
CPSactual_ T3 ______
CPSdiscrep_ T3 ______

IF CODED AS 12 (OTHER) FREE TEXT FIELD TO ENTER SEQUENCE

☐ ☐ ☐ ☐ ☐

APPENDIX I: Profile of Mood States - Short Form

Below is a list of words that describe feelings people have. Please read each one carefully. Then, circle the one number to the right which best describes how YOU have been feeling DURING THE PAST WEEK, INCLUDING TODAY.

	Not at all	A little	Moderately	Quite a bit	Extremely
Tense..	0	1	2	3	4
Angry..	0	1	2	3	4
Worn out..	0	1	2	3	4
Unhappy..	0	1	2	3	4
Lively..	4	3	2	1	0
Confused..	0	1	2	3	4
Peeved...	0	1	2	3	4
Sad..	0	1	2	3	4
Active..	4	3	2	1	0
On edge...	0	1	2	3	4
Grouchy...	0	1	2	3	4
Unable to concentrate..........................	0	1	2	3	4

	Not at all	A little	Moderately	Quite a bit	Extremely
Blue	0	1	2	3	4
Energetic	4	3	2	1	0
Hopeless	0	1	2	3	4
Uneasy	0	1	2	3	4
Restless	0	1	2	3	4
Fatigued	0	1	2	3	4
Annoyed	0	1	2	3	4
Discouraged	0	1	2	3	4
Resentful	0	1	2	3	4
Nervous	0	1	2	3	4
Miserable	0	1	2	3	4
Cheerful	4	3	2	1	0
Bitter	0	1	2	3	4
Exhausted	0	1	2	3	4
Anxious	0	1	2	3	4

	Not at all	A little	Moderately	Quite a bit	Extremely
Helpless..	0	1	2	3	4
Weary...	0	1	2	3	4
Bewildered.......................................	0	1	2	3	4
Furious...	0	1	2	3	4
Full of pep.......................................	4	3	2	1	0
Worthless..	0	1	2	3	4
Forgetful...	0	1	2	3	4
Vigorous...	4	3	2	1	0
Uncertain about things.........................	0	1	2	3	4
Bushed...	0	1	2	3	4

APPENDIX J: Negative Thoughts Inventory

Women who have been treated for breast cancer often experience a number of events that remind them about possible breast cancer recurrence. During such events, women are likely to have some troublesome thoughts.

Below is a list of troublesome thoughts. Please read each one and then circle the one number that describes how often you have that thought during an event that reminds you about the possibility of breast cancer recurrence. Circle only one number for each thought and do not skip any items.

	Never	**Seldom**	**Sometimes**	**Often**	**Always**
The doctor might be wrong.	1	2	3	4	5
My disease is worse than hers.	1	2	3	4	5
If her cancer has spread, then mine will also.	1	2	3	4	5
My husband (partner) will think I'm foolish for paying so much attention to my body.	1	2	3	4	5
No one wants to hear about my fear of recurrence.	1	2	3	4	5
It is not fair that I have to live with this constant worry about recurrence.	1	2	3	4	5
The headache or backache (or any other new physical problem) is getting worse, it must be cancer.	1	2	3	4	5
This pain could only mean cancer.	1	2	3	4	5
I know the doctor is not telling me the truth.	1	2	3	4	5
They are taking too long to read the results of my test, it must be bad.	1	2	3	4	5
They know something they are not telling me.	1	2	3	4	5
I am going to die from breast cancer.	1	2	3	4	5

	Never	Seldom	Sometimes	Often	Always
I am helpless to do anything about the future course of my disease.	1	2	3	4	5
How often do you have troublesome thoughts about things <u>other than</u> the possibility of recurrence?	1	2	3	4	5
How often are you able to control these troublesome thoughts and reduce their frequency?	5	4	3	2	1

Reference List

Aiken, L. S., & West, S. G. (1991a). Multiple regression: Testing and interpreting interactions. Thousand Oaks, CA: Sage.

Aiken, L. S., & West, S. G. (1991b). Multiple regression: Testing and interpreting interactions. Thousand Oaks, CA: Sage.

American Cancer Society. (2000). Atlanta, GA: American Cancer Society.

American Cancer Society. (2001a). Atlanta, Georgia: American Cancer Society.

American Cancer Society. (2001b). Atlanta, Georgia: American Cancer Society.

American Cancer Society . (2002). Atlanta, GA: American Cancer Society.

Anllo, L. M. (2000). Sexual life after breast cancer. J Sex Marital Ther, 26(3), 241-8.

Ashing-Giwa, K., Ganz, P. A., & Petersen, L. (1999). Quality of life of African-American and white long term breast carcinoma survivors. Cancer, 85(2), 418-26.

Ashing-Giwa, K., & Ganz, P. (1997). Understanding the Breast Cancer Experience of African-American Women. Journal of Psychosocial Oncology, 15(2), 19-35.

Aziz, N. M., & Rowland, J. H. (2002). Cancer survivorship research among ethnic minority and medically underserved groups. Oncol Nurs Forum, 29(5), 789-801.

Baturka, N., Hornsby, P. P., & Schorling, J. B. (2000). Clinical implications of body image among rural African-American women. J Gen Intern Med, 15(4), 235-41.

Beaver, K., Bogg, J., & Luker, K. A. (1999). Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. Health Expect, 2(4), 266-276.

Beaver, K., Luker, K. A., Owens, R. G., Leinster, S. J., Degner, L. F., & Sloan, J. A. (1996). Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs, 19(1), 8-19.

Beder, J. (1995). Perceived social support and adjustment to mastectomy in socioeconomically disadvantaged black women. Soc Work Health Care, 22(2), 55-71.

Beisecker, A. E. (1988). Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. Gerontologist, 28(3), 330-335.

Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. Medical Care, 28(1), 19-28.

Bennett, S. J. (1993). Relationships among selected antecedent variables and coping effectiveness in postmyocardial infarction patients. Res Nurs Health, 16(2), 131-9.

Bibb, S. C. (2001). The relationship between access and stage at diagnosis of breast cancer in African American and Caucasian women. Oncol Nurs Forum, 28(4), 711-9.

Blanchard, C. G., Labrecque, M. S., Ruckdeschel, J. C., & Blanchard, E. B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. Soc Sci Med, 27(11), 1139-45.

Bleiker, E. M., Pouwer, F., van der Ploeg, H. M., Leer, J. W., & Ader, H. J. (2000). Psychological distress two years after diagnosis of breast cancer: frequency and prediction. Patient Educ Couns, 40(3), 209-17.

Bollen, K. (1989). Structural Equations with Latent Variables. New York: Wiley.

Boon, H., Brown, J. B., Gavin, A., Kennard, M. A., & Stewart, M. (1999). Breast cancer survivors' perceptions of complementary/alternative medicine (CAM): making the decision to use or not to use. Qual Health Res, 9(5), 639-53.

Borgers, R., Mullen, P. D., Meertens, R., Rijken, M., Eussen, G., Plagge, I., Visser, A. P., & Blijham, G. H. (1993). The information-seeking behavior of cancer outpatients: a description of the situation. Patient Educ Couns, 22(1), 35-46.

Borges, S., & Waitzkin, H. (1995). Women's narratives in primary care medical encounters. Women & Health, 23 (1), 29-56.

Bourjolly, J. N. (1998). Differences in religiousness among black and white women with breast cancer. Soc Work Health Care, 28(1), 21-39.

Bourjolly, J. N., Kerson, T. S., & Nuamah, I. F. (1999). A comparison of social functioning among black and white women with breast cancer. Soc Work Health Care, 28(3), 1-20.

Bower, J. E., Ganz, P. A., Desmond, K. A., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2000). Fatigue in breast cancer survivors: occurrence, correlates, and impact on quality of life. J Clin Oncol, 18(4), 743-53.

Braden, C. J., Mishel, M. H., & Longman, A. (1995). Efficacy of the self-help course for women receiving treatment for breast cancer. Oncology Nursing Forum, 22, 350.

Braden, C. J., Mishel, M. H., & Longman, A. J. (1998). Self-Help Intervention Project. Women receiving breast cancer treatment. Cancer Practice, 6(2), 87-98.

Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, LW., & Russell, J. A. (2000a). Communication in the Management of Uncertainty: The case of Persons Living with HIV or AIDS. Communication Monographs, 67(1), 63-84.

Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, LW., & Russell, J. A. (2000b). Communication in the Management of Uncertainty: The case of Persons Living with HIV or AIDS. Communication Monographs, 67(1), 63-84.

Brashers, D. E., Neidig, J. L., Reynolds, N. R., & Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory. J Assoc Nurses AIDS Care, 9(1), 66-77.

Budin, W. C. (1998). Psychosocial adjustment to breast cancer in unmarried women. Res Nurs Health, 21(2), 155-66.

Byrne, B. M. (2001). Structural Equation Modeling with AMOS: Basic Concepts, Applications, and Programming. Mahwah, NJ: Lawrence Erlbaum Associates.

Calvin, R. L., & Lane, P. L. (1999). Perioperative uncertainty and state anxiety of orthopaedic surgical patients. Orthop Nurs, 18(6), 61-6.

Cameron, S., & Horsburgh, M. E. (1998). Comparing issues faced by younger and older women with breast cancer. Can Oncol Nurs J, 8(1), 40-4.

Carpenter, J. S., Johnson, D., Wagner, L., & Andrykowski, M. (2002). Hot flashes and related outcomes in breast cancer survivors and matched comparison women. Oncol Nurs Forum, 29(3), E16-25.

Carroll, D. L., Hamilton, G. A., & McGovern, B. A. (1999). Changes in health status and quality of life and the impact of uncertainty in patients who survive life-threatening arrhythmias. Heart Lung, 28(4), 251-60.

Carter, B. J. (1997). Women's experiences of lymphedema. Oncol Nurs Forum, 24(5), 875-82.

Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. Ann Intern Med, 92(6), 832-6.

Cegala, D. J. (1997). A study of doctors' and patients' communication during a primary care consultation: implications for communication training. J Health Commun, 2(3), 169-94.

Cegala, D. J., Marinelli, T., & Post, D. (2000). The effects of patient communication skills training on compliance. Arch Fam Med, 9(1), 57-64.

Christman, N. J. (1990). Uncertainty and adjustment during radiotherapy. Nurs Res, 39(1), 17-20, 47.

Christman, N. J., McConnell, E. A., Pfeiffer, C., Webster, K. K., Schmitt, M., & Ries, J. (1988). Uncertainty, coping, and distress following myocardial infarction: transition from hospital to home. Research in Nursing & Health, 11(2), 71-82.

Cimprich, B., & Ronis, D. L. (2001). Attention and symptom distress in women with and without breast cancer. Nurs Res, 50(2), 86-94.

Cohen, M. H. (1995a). The stages of the prediagnostic period in chronic, life-threatening childhood illness: a process analysis. Research in Nursing & Health, 18(1), 39-48.

Cohen, M. H. (1995b). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. Qualitative Health Research, 5(1), 63-77.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (1998). Beyond body image: the experience of breast cancer. Oncol Nurs Forum, 25(5), 835-41.

Comstock, L. M., Hooper, E. M., Goodwin, J. M., & Goodwin, J. S. (1982). Physician behaviors that correlate with patient satisfaction. J Med Educ, 57(2), 105-12.

Cooper-Patrick, L., Gallo, J. J., Gonzales, J. J., Vu, H. T., Powe, N. R., Nelson, C., & Ford, D. E. (1999). Race, gender, and partnership in the patient-physician relationship. JAMA, 282(6), 583-9.

Cordova, M. J., Cunningham, L. L., Carlson, C. R., & Andrykowski, M. A. (2001). Social constraints, cognitive processing, and adjustment to breast cancer. J Consult Clin Psychol, 69(4), 706-11.

Crigger, N. J. (1996). Testing an uncertainty model for women with multiple sclerosis. Adv Nurs Sci, 18(3), 37-47.

Crooks, D. L. (2001). Older women with breast cancer: new understandings through grounded theory research. Health Care Women Int, 22(1-2), 99-114.

Curran, L. S., Andrykowski, M. A., & Studts, J. L. (1995). Short form of the Profile of Mood States (POMS-SF): Psychometric information. Psychologica Assessment, 7(1), 80-83.

Davis, L. L. (1990). Illness uncertainty, social support, and stress in recovering individuals and family care givers. Applied Nursing Research, 3(2), 69-71.

Davis, T. C., Williams, M. V., Marin, E., Parker, R. M., & Glass, J. (2002). Health literacy and cancer communication. CA Cancer J Clin, 52(3), 134-49.

Deane, K. A., & Degner, L. F. (1998). Information needs, uncertainty, and anxiety in women who had a breast biopsy with benign outcome . Cancer Nurs, 21(2), 117-26.

Decruyenaere, M., Evers-Kiebooms, G., Cloostermans, T. , Boogaerts, A., Demyttenaere, K., Dom, R., & Fryns, J. P. (2003). Psychological distress in the 5-year period after predictive testing for Huntington's disease. Eur J Hum Genet, 11(1), 30-8.

Degner, L. (1992). Patient participation in treatment decision making. Axone, 14(1),13-4.

Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., Bilodeau, B., Watson, P., & Mueller, B. (1997a). Information needs and decisional preferences in women with breast cancer. JAMA, 277(18), 1485-92.

Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., Bilodeau, B., Watson, P., & Mueller, B. (1997b). Information needs and decisional preferences in women with breast cancer. JAMA, 277(18), 1485-92.

Degner, L. F., & Sloan, J. A. (1992). Decision making during serious illness: what role do patients really want to play? J Clin Epidemiol, 45(9), 941-50.

Degner, L. F., Sloan, J. A., & Venkatesh, P. (1997). The Control Preferences Scale. Can J Nurs Res, 29(3), 21-43.

Dirksen, S. R. (2000). Predicting well-being among breast cancer survivors. J Adv Nurs, 32(4), 937-43.

Dorval, M., Maunsell, E., Deschenes, L., Brisson, J., & Masse, B. (1998). Long-term quality of life after breast cancer: comparison of 8-year survivors with population controls. J Clin Oncol, 16(2), 487-94.

Dow, K. H., Ferrell, B. R., Leigh, S., Ly, J., & Gulasekaram, P. (1996). An evaluation of the quality of life among long-term survivors of breast cancer. Breast Cancer Res Treat, 39(3), 261-73.

Ende, J., Kazis, L., Ash, A., & Moskowitz, M. A. (1989). Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. J Gen Intern Med, 4(1), 23-30.

Farmer, B. J., & Smith, E. D. (2002). Breast cancer survivorship: are african american women considered? A concept analysis. Oncol Nurs Forum, 29(5), 779-87.

Ferketich, S. (1990). Internal consistency estimates of reliability. Research in Nursing and Health, 13, 437-440.

Ferrans, C. E. (1994). Quality of life through the eyes of survivors of breast cancer. Oncol Nurs Forum, 21(10), 1645-51.

Ferrell, B. R., Grant, M., Funk, B., Garcia, N., Otis-Green, S., & Schaffner, M. L. (1996). Quality of life in breast cancer. Cancer Pract, 4(6), 331-40.

Ferrell, B. R., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1997a). Quality of life in breast cancer. Part I: Physical and social well- being. Cancer Nurs, 20(6), 398-408.

Ferrell, B. R., Grant, M. M., Funk, B., Otis-Green, S., & Garcia, N. (1997b). Quality of life in breast cancer survivors as identified by focus groups. Psychooncology, 6(1), 13-23.

Ferrell, B. R., Grant, M. M., Funk, B. M., Otis-Green, S. A., & Garcia, N. J. (1998). Quality of life in breast cancer survivors: implications for developing support services. Oncol Nurs Forum, 25(5), 887-95.

Fleury, J., Kimbrell, L. C., & Kruszewski, M. A. (1995). Life after a cardiac event: women's experiences in healing. Heart & Lung: Journal of Critical Care, 24(6), 474-482.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res, 12(3), 189-98.

Ford, L. A., Babrow, A. S., & Stohl, C. (1996). Social Support Messages and the Management of Uncertainty in the Experience of Breast Cancer: An Application of Problematic Integration Theory. Communication Monographs, 63(3), 189-207.

Gabbard-Alley, A. S. (1995). Health communication and gender: A review and critique. Health Communication, 7, 35-54.

Galloway, S. C., & Graydon, J. E. (1996). Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. Cancer Nursing, 19, 112-117.

Ganz, P. A., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M. L., & Petersen, L. (1996). Breast cancer survivors: psychosocial concerns and quality of life. Breast Cancer Research & Treatment, 38(2), 183-99.

Ganz, P. A., Lee, J. J., Sim, M. S., Polinsky, M. L., & Schag, C. A. (1992). Exploring the influence of multiple variables on the relationship of age to quality of life in women with breast cancer. J Clin Epidemiol, 45(5), 473-85.

Ganz, P. A., Rowland, J. H., Desmond, K., Meyerowitz, B. E., & Wyatt, G. E. (1998). Life after breast cancer: understanding women's health-related quality of life and sexual functioning. J Clin Oncol, 16(2), 501-14.

Germino, B. B., Mishel, M. H., Belyea, M., Harris, L., Ware, A., & Mohler, J. (1998). Uncertainty in prostate cancer: ethnic and family patterns. Cancer Practice: a Multidisciplinary Journal of Cancer Care, 6(2), 107-113.

Gil, K. M., Mishel, M. H., Belyea, M., Germino, B., Porter, L. S., LeNey, I. C., & Stewart, J. (2002). Triggers of uncertainty about recurrence and treatment side effects in long term older breast cancer survivors. In Press.

Gil, K. M., Wilson, J. J., Edens, J. L., Webster, D. A., Abrams, M. A., Orringer, E., Grant, M., Clark, W. C., & Janal, M. N. (1996). Effects of cognitive coping skills training on coping strategies and experimental pain sensitivity in African American adults with sickle cell disease. Health Psychol, 15(1), 3-10.

Girgis, A., Boyes, A., Sanson-Fisher, R. W., & Burrows, S. (2000). Perceived needs of women diagnosed with breast cancer: rural versus urban location. Aust N Z J Public Health, 24(2), 166-73.

Goldberg, R., Guadagnoli, E., Silliman, R. A., & Glicksman, A. (1990). Cancer patients' concerns: congruence between patients and primary care physicians. J Cancer Educ, 5(3), 193-9.

Gollop, C. J. (1997). Health information-seeking behavior and older African American women. Bull Med Libr Assoc, 85(2), 141-6.

Gotay, C. C., Holup, J. L., & Pagano, I. (2002). Ethnic differences in quality of life among early breast and prostate cancer survivors. Psychooncology, 11(2), 103-13.

Gray, R. E., Fitch, M., Greenberg, M., Hampson, A., Doherty, M., & Labrecque, M. (1998). The information needs of well, longer-term survivors of breast cancer. Patient Educ Couns, 33(3), 245-55.

Greene, M. G., Adelman, R., Charon, R., & Hoffman, S. (1986). Ageism in the medical encounter: an exploratory study of the doctor- elderly patient relationship. Lang Commun, 6(1-2), 113-24.

Greene, M. G., Adelman, R. D., Friedmann, E., & Charon, R. (1994). Older patient satisfaction with communication during an initial medical encounter. Social Science & Medicine, 38(9), 1279-1288.

Grootenhuis, M. A., & Last, B. F. (1997). Predictors of parental emotional adjustment to childhood cancer. Psychooncology, 6(2), 115-28.

Gudex, C. M. (1995). Health-related quality of life in endstage renal failure. Qual Life Res, 4(4), 359-66.

Guillory, J. (1987). Ethnic perspective of cancer nursing: the Black American. Oncol Nurs Forum, 14(3), 66-9.

Halstead, M. T., & Fernsler, J. I. (1994). Coping strategies of long-term cancer survivors. Cancer Nurs, 17(2), 94-100.

Hanson Frost, M., Suman, V. J., Rummans, T. A., Dose, A. M., Taylor, M., Novotny, P., Johnson, R., & Evans, R. E. (2000). Physical, psychological and social well-being of women with breast cancer: the influence of disease phase. Psycho-Oncology, 9(3), 221-31.

Hawthorne, M. H., & Hixon, M. E. (1994). Functional status, mood disturbance and quality of life in patients with heart failure. Progress in Cardiovascular Nursing, 9(1), 22-32.

Hayes, K. S. (1998). Randomized trial of geragory-based medication instruction in the emergency department. Nursing Research, 47 (4), 211-218.

Helmes, A. W., Bowen, D. J., & Bengel, J. (2002). Patient preferences of decision-making in the context of genetic testing for breast cancer risk. Genet Med, 4(3), 150-7.

Hill-Harmon, M. B., Greenlee, R., & Thun, M. J. (2000). Atlanta, GA: American Cancer Society, Inc.

Hilton, B. A. (1988). The phenomenon of uncertainty in women with breast cancer. Issues in Mental Health Nursing, 9(3), 217-238.

Hilton, B. A. (1989). The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. Journal of Behavioral Medicine , 12(1), 39-54.

Hilton, B. A. (1993). Issues, problems, and challenges for families coping with breast cancer. Seminars in Oncology Nursing, 9, 88-1000.

Hilton, B. A. (1994). The Uncertainty Stress Scale: its development and psychometric properties. Canadian Journal of Nursing Research , 26(3), 15-30.

Hoyle, R. H. (1995). The Structural Equation Modeling Approach: Basic Concepts and Fundmental Issues. in R. H. Hoyle (Editor), Structural Equation Modeling: Concepts, Issues, and Applications (pp. 1-15). Thousand Oaks: Sage.

Hoyle, R., & Panter, A. (1995). Writing about structural equation models. in R.H. Hoyle (ed), Structural Equation Modeling: Concepts, Issues, and Applications (pp. 158-176). Thousand Oaks: Sage.

Hull, M. M. (2000). Lymphedema in women treated for breast cancer. Semin Oncol Nurs, 16(3), 226-37.

Hunter, C. P. (2000). Epidemiology, stage at diagnosis, and tumor biology of breast carcinoma in multiracial and multiethnic populations. Cancer, 88(5 Suppl), 1193-202.

Jaccard, J., & Wan, C. K. (1995). Measurement error in the analysis of interaction effects between continuous predictors using multiple regression: Multiple indicator and structural equation approaches. Psychological Bulletin, 117(2), 348-357.

Jacobs, L., & Hobbie, W. (2002). The Living Well After Cancer Program: An advanced practice model of care. Oncology Nursing Forum, 29(4), 637-638.

Johnson, J. D. (2002). On contexts and information seeking. paper presented at the National Communication Association conference, New Orleans .

Johnson, J. D., Roberts, C. S., Cox, C. E., Reintgen, D. S., Levine, J. S., & Parsons, M. (1996). Breast cancer patients' personality style, age, and treatment decision making. J Surg Oncol, 63(3), 183-6.

Johnson-Vickberg, S. M. (2001). Fears about breast cancer recurrence. Cancer Pract, 9(5), 237-43.

Joreskog, K., & Yang, F. (1996). Nonlinear structural equation models: The Kenny-Judd model with interaction effects. in G. Marcoulides, & R. Scumaker (eds), Advanced Sructural Equation Models: Issues and Techniques. (pp. 57-88). Mahwah NJ: Lawrence Erlbaum.

Joreskog, K. G. (1998). Interaction and nonlinear modeling: Issues and approaches. in G. A. M. R. E. Schumaker (Ed), Interaction and nonlinear effects in structural equation modeling. (pp. 239-250). Maywah, NJ: Lawrence Erlbaum.

Kaplan, S. H., Gandek, B., Greenfield, S., Rogers, W., & Ware, J. E. (1995). Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. Med Care, 33(12), 1176-87.

Korsch, B. M., Gozzi, E. K., & Francis, V. (1968). Gaps in doctor-patient communication. 1. Doctor-patient interaction and patient satisfaction. Pediatrics, 42(5), 855-871.

Kroencke, D. C., Denney, D. R., & Lynch, S. G. (2001). Depression during exacerbations in multiple sclerosis: the importance of uncertainty. Mult Scler, 7(4), 237-42.

Krupat, E., Irish, J. T., Kasten, L. E., Freund, K. M., Burns, R. B., Moskowitz, M. A., & McKinlay, J. B. (1999). Patient assertiveness and physician decision-making among older breast cancer patients. Social Science & Medicine, 49(4), 449-57.

Landis, B. J. (1996). Uncertainty, spiritual well-being, and psychosocial adjustment to chronic illness. Issues in Mental Health Nursing, 17(3), 217-231.

Lazarus, R. S. (1974). Psychological stress and coping in adaptation and illness. International Journal of Psychiatry in Medicine, 5(4), 321-333.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Leedham, B., & Ganz, P. A. (1999). Psychosocial concerns and quality of life in breast cancer survivors. Cancer Invest, 17(5), 342-8.

Leigh, S. (1992). Myths, monsters, and magic: personal perspectives and professional challenges of survival. Oncol Nurs Forum, 19(10), 1475-80.

Lemaire, G. S., & Lenz, E. R. (1995). Perceived uncertainty about menopause in women attending an educational program. Int J Nurs Stud, 32(1), 39-48.

Lerman, C., Daly, M., Walsh, W. P., Resch, N., Seay, J., Barsevick, A., Birenbaum, L., Heggan, T., & Martin, G. (1993). Communication between patients with breast cancer and health care providers. Determinants and implications. Cancer, 72(9), 2612-20.

Lerman, C. E., Brody, D. S., Caputo, G. C., Smith, D. G., Lazaro, C. G., & Wolfson, H. G. (1990). Patients' Perceived Involvement in Care Scale: relationship to attitudes about illness and medical care. J Gen Intern Med, 5(1), 29-33.

Levinson, W., & Roter, D. (1993). The effects of two continuing medical education programs on communication skills of practicing primary care physicians. J Gen Intern Med, 8(6), 318-24.

Loescher, L. J., Clark, L., Atwood, J. R., Leigh, S., & Lamb, G. (1990). The impact of the cancer experience on long-term survivors. Oncol Nurs Forum, 17(2), 223-9.

Longman, A. J., Braden, C. J., & Mishel, M. H. (1996). Side effects burden in women with breast cancer. Cancer Pract, 4(5), 274-80.

Longman, A. J., Braden, C. J., & Mishel, M. H. (1999). Side-effects burden, psychological adjustment, and life quality in women with breast cancer: pattern of association over time. Oncol Nurs Forum, 26(5), 909-15.

Lubeck, D. P., Kim, H., Grossfeld, G., Ray, P., Penson, D. F., Flanders, S. C., & Carroll, P. R. (2001). Health related quality of life differences between black and white men with prostate cancer: data from the cancer of the prostate strategic urologic research endeavor. J Urol, 166(6), 2281-5.

Ludwick, R., Rushing, B., & Biordi, D. L. (1994). Breast cancer and the older woman: information and images. Health Care Women Int, 15(3), 235-42.

Luker, K. A., Beaver, K., Leinster, S. J., & Owens, R. G. (1996). Information needs and sources of information for women with breast cancer: a follow-up study. J Adv Nurs, 23(3), 487-95.

MacCallum, R., Browne, M., & Sugawara, H. (1996). Power Analysis and Determination of Sample Size for Covariance Structure Modeling. Psychological Methods, 1(2), 130-149.

Makoul, G., Arntson, P., & Schofield, T. (1995). Health promotion in primary care: physician-patient communication and decision making about prescription medications. Soc Sci Med, 41(9), 1241-54.

Mann, S., Sripathy, K., Siegler, E. L., Davidow, A., Lipkin, M., & Roter, D. L. (2001). The medical interview: differences between adult and geriatric outpatients. J Am Geriatr Soc, 49(1), 65-71.

Mason-Hawkes, J., & Holm, K. (1989). Causal modeling: a comparison of path analysis and LISREL. Nurs Res, 38 (5), 312-4.

Mast, M. E. (1995). Adult uncertainty in illness: a critical review of research... including commentary by Mishel MH. Scholarly Inquiry for Nursing Practice, 9(1), 3-29.

Mast, M. E. (1998a). Correlates of fatigue in survivors of breast cancer. Cancer Nurs, 21(2), 136-42.

Mast, M. E. (1998b). Survivors of breast cancer: illness uncertainty, positive reappraisal, and emotional distress. Oncol Nurs Forum, 25(3), 555-62.

Maxwell, S. E., & Delaney, H. D. (2000). Designing Experiments and Analyzing Data: A Model Comparison Perspective. Mahwah, New Jersey: Lawrence Erlbaum Associates.

McCorkle, R., & Quint-Benoliel, J. (1983). Symptom distress, current concerns and mood disturbance after diagnosis of life-threatening disease. Soc Sci Med, 17(7), 431-8.

McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. Cancer Nurs, 1(5), 373-8.

McCormick, K. M. (2002). A concept analysis of uncertainty in illness. J Nurs Scholarsh, 34(2), 127-31.

McKinley, E. D. (2000). Under Toad days: surviving the uncertainty of cancer recurrence. Ann Intern Med, 133 (6), 479-80.

McKinley, E. D., Garrett, J. M., Evans, A. T., & Danis, M. (1996). Differences in end-of-life decision making among black and white ambulatory cancer patients. J Gen Intern Med, 11(11), 651-6.

Meyerowitz, B. E., Desmond, K. A., Rowland, J. H., Wyatt, G. E., & Ganz, P. A. (1999). Sexuality following breast cancer. J Sex Marital Ther, 25(3), 237-50.

Meyerowitz, B. E., Richardson, J., Hudson, S., & Leedham, B. (1998). Ethnicity and cancer outcomes: behavioral and psychosocial considerations. Psychol Bull, 123(1), 47-70.

Michielutte, R., & Diseker, R. A. (1982). Racial differences in knowledge of cancer: a pilot study. Soc Sci Med, 16(3), 245-52.

Mishel, M. H. (1981). The measurement of uncertainty in illness. Nursing Research , 30, 258-263.

Mishel, M. H. (1984). Perceived uncertainty and stress in illness. Research in Nursing & Health, 7(3), 163-71.

Mishel, M. H. (1988). Uncertainty in illness. Image: The Journal of Nursing Scholarship, 20(4), 225-232.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. Image: The Journal of Nursing Scholarship, 22(4), 256-62.

Mishel, M. H. (1997). Uncertainty in acute illness. Annual Review of Nursing Research, 15, 57-80.

Mishel, M. H., Belyea, M., Germino, B. B., Stewart, J. L., Bailey, D. E. Jr, Robertson, C., & Mohler, J. (2002a). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects: nurse-delivered psychoeducational intervention over the telephone. Cancer, 94(6), 1854-66.

Mishel, M. H., Belyea, M., Germino, B. B., Stewart, J. L., Bailey, D. E. Jr, Robertson, C., & Mohler, J. (2002b). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects: nurse-delivered psychoeducational intervention over the telephone. Cancer, 94(6), 1854-66.

Mishel, M. H., & Braden, C. J. (1988). Finding meaning: antecedents of uncertainty in illness. Nursing Research, 37(2), 98-103-127.

Mishel, M. H., & Clayton, M. F. (in press). Uncertainty in Illness Theories. in M.J. Smith , & P. Liehr Eds (Eds), Middle Range Theory in Advanced Practice Nursing . New York: Springer Publishing.

Mishel, M. H., Germino, G., Gil, K., Carlton-LaNey, I., Belyea, M., Stewart, J., Washington, C., Clayton, M., & Yin, G. (2002). Triggers of uncertainty about recurrence and treatment side effects in older breast cancer survivors. Poster presented at Cancer Survivorship: Resilience Across the Lifespan. ., Washinton DC: National Cancer Institute and American Cancer Society.

Mishel, M. H., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychosocial adjustment in patients newly diagnosed with gynecological cancer. Cancer Nurs, 7(4), 291-9.

Mishel, M. (1999). Managing Uncertainty in Older Breast Cancer Survivors 5R01 CA 78955-03.

Mishel, M., Germino, B., Belyea, M., Harris, L., Stewart, J., Bailey, D., Mohler, J., & Robertson, C. (2001). Helping Patients with localized prostate cancer: Managing after treatment. in SG Funk, EM Tornquist, J Leeman, M Miles, & JS Harrell (Eds), Key Aspects of Preventing and Managing Chronic Illness (pp. 235-247). NY: Springer.

Mishel, M., & Sorenson, D. (1991). Coping with uncertainty in gynecological cancer: A test of the mediating function of mastery and coping. Nursing Research, 40, 167-171.

Moinpour, C. M., Hayden, K. A., Thompson, I. M., Feigl, P., & Metch, B. (1990). Quality of life assessment in Southwest Oncology Group trials. Oncology (Huntingt), 4(5), 79-84, 89; discussion 104.

Molleman, E., Krabbendam, P. J., Annyas, A. A., Koops, H. S., Sleijfer, D. T., & Vermey, A. (1984). The significance of the doctor-patient relationship in coping with cancer. Social Science & Medicine, 18(6), 475-480.

Moore, R. J. (2001). African American women and breast cancer: notes from a study of narrative. Cancer Nurs, 24(1), 35-42; quiz 43.

Moormeier, J. (1996). Breast cancer in black women. Ann Intern Med, 124(10), 897-905.

Morasso, G., Capelli, M., Viterbori, P., Di Leo, S., Alberisio, A., Costantini, M., Fiore, M., Saccani, D., Zeitler, G., Verzolatto, N., Tirelli, W., Lazzari, L., Partinico, M., Borzoni, G., Savian, C., Obertino, E., Zotti, P., Ivaldi, G. P., & Henriquet, F. (1999). Psychological and symptom distress in terminal cancer patients with met and unmet needs. J Pain Symptom Manage, 17(6), 402-9.

Morrow, M. (1994). Breast disease in elderly women. Surg Clin North Am, 74(1), 145-61.

Nelson, J. P. (1996). Struggling to gain meaning: living with the uncertainty of breast cancer. Advances in Nursing Science, 18(3), 59-76.

Norris, A. E. (2001a). Path Analysis. in B.H. Munro (Ed), Statistical Methods for Health Care Research (4th ed., pp. 355-378). Philadelphia: Lippincott Williams & Wilkins.

Norris, A. E. (2001b). Structural Equation Modeling. in B.H. Munro (Ed), Statistical Methods for Health Care Research (4th ed., pp. 379-404). Philadelphia: Lippincott Williams & Wilkins.

Northouse, L. L., Caffey, M., Deichelbohrer, L., Schmidt, L., Guziatek-Trojniak, L., West, S., Kershaw, T., & Mood, D. (1999). The quality of life of African American women with breast cancer. Res Nurs Health, 22(6), 449-60.

Northouse, L. L., Jeffs, M., Cracchiolo-Caraway, A., Lampman, L., & Dorris, G. (1995). Emotional distress reported by women and husbands prior to a breast biopsy. Nurs Res, 44(4), 196-201.

O'Hare, P. A., Malone, D., Lusk, E., & McCorkle, R. (1993). Unmet needs of black patients with cancer posthospitalization: a descriptive study. Oncol Nurs Forum, 20(4), 659-64.

Ohlen, J., Bengtsson, J., Skott, C., & Segesten, K. (2002). Being in a lived retreat--embodied meaning of alleviated suffering. Cancer Nurs, 25(4), 318-25.

Okuyama, T., Akechi, T., Kugaya, A., Okamura, H., Imoto, S., Nakano, T., Mikami, I., Hosaka, T., & Uchitomi, Y. (2000). Factors correlated with fatigue in disease-free breast cancer patients: application of the Cancer Fatigue Scale. Support Care Cancer, 8(3), 215-22.

Paci, E., Cariddi, A., Barchielli, A., Bianchi, S., Cardona, G., Distante, V., Giorgi, D., Pacini, P., Zappa, M., & Del Turco, M. R. (1996). Long-term sequelae of breast cancer surgery. Tumori, 82(4), 321-4.

Paget, M. A. (1983). On the work of talk: Studies in misunderstandings. in S.Fisher & A.D.Todd. The Social organization of doctor-patient communication (pp. 54-74). Washington, D.C. Center for Applied Linguistics .

Parascandola, M., Hawkins, J., & Danis, M. (2002). Patient autonomy and the challenge of clinical uncertainty. Kennedy Inst Ethics J, 12(3), 245-64.

Patterson, J. M., Leonard, B. J., & Titus, J. C. (1992). Homecare for medically fragile children: Impact on family health and well-being. Developmental and Behavioral Pediatrics, 13(4), 248-255.

Pedhazer E.J. (1997). Multiple Regression in Behavioral Research: Explanation and Prediction. 3rd ed.,). Fort Worth, TX: Harcourt Brace.

Pedhazer, E. J., & Schmelkin, L. P. (1991). Measurement, Design,and Analysis: An Integrated Approach. Hillsdale, New Jersey: Lawrence Erlbaum Associates .

Pelusi, J. (1997). The lived experience of surviving breast cancer. Oncology Nursing Forum, 24(8), 1343-1353.

Polinsky, M. L. (1994). Functional status of long-term breast cancer survivors: demonstrating chronicity. Health Soc Work, 19(3), 165-73.

Polit, D. F. (1996). Data analysis and statistics for nuring research. Stamford, CT: Appleton & Lange.

Powe, B. D. (1996). Cancer fatalism among African-Americans: a review of the literature. Nurs Outlook, 44(1), 18-21.

Pyke-Grimm, K. A., Degner, L., Small, A., & Mueller, B. (1999). Preferences for participation in treatment decision making and information needs of parents of children with cancer: a pilot study. J Pediatr Oncol Nurs, 16(1), 13-24.

Ramfelt, E., Langius, A., Bjorvell, H., & Nordstrom, G. (2000). Treatment decision-making and its relation to the sense of coherence and the meaning of the disease in a group of patients with colorectal cancer. Eur J Cancer Care (Engl), 9(3), 158-65.

Rees A. (2000). Trends in medical consumerism. in A Rees (Ed), Consumer Health Information Source Book (pp. 1-22). Phoenix: Oryx Press.

Rhodes, V. A., McDaniel, R. W., Homan, S. S., Johnson, M., & Madsen, R. (2000). An instrument to measure symptom experience. Symptom occurrence and symptom distress. Cancer Nurs, 23(1), 49-54.

Ritz, L. J., Nissen, M. J., Swenson, K. K., Farrell, J. B., Sperduto, P. W., Sladek, M. L., Lally, R. M., & Schroeder, L. M. (2000). Effects of advanced nursing care on quality of life and cost outcomes of women diagnosed with breast cancer. Oncol Nurs Forum, 27(6), 923-32.

Rodrigue J.R. (1997). An examination of race diffrences in patients' psychological adjustment to cancer. Journal of Clinical Psychology and Medical Screening, 4, 271-280.

Roter, D. L., & Hall, J. A. (1992). Doctors talking to patients/ patients talking to doctors: Improving communication in medical visits. Westport, CT: Auburn House.

Roter, D. L., Hall, J. A., & Katz, N. R. (1988). Patient-Physician Communication: A descriptive summary of the literature. Patient Education and Counseling, 12, 99-119.

Roter, D. L., Larson, S., Fischer, G. S., Arnold, R. M., & Tulsky, J. A. (2000). Experts practice what they preach: A descriptive study of best and normative practices in end-of-life discussions. Arch Intern Med, 160(22), 3477-85.

Rowland, J. H., Desmond, K. A., Meyerowitz, B. E., Belin, T. R., Wyatt, G. E., & Ganz, P. A. (2000). Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors. J Natl Cancer Inst, 92(17), 1422-9.

Rutter, D., Iconomou, G., & Quine, L. (1996). Doctor-Patient Communication and Outcome in Cancer Patients: An Intervention. Psychology and Health, 12, 57-71.

Sammarco, A. (2001a). Psychosocial stages and quality of life of women with breast cancer. Cancer Nurs, 24(4), 272-7.

Sammarco, A. (2001b). Perceived Social Support, Uncertainty, and Quality of Life of Younger Breast Cancer Survivors. Cancer Nursing, 24(3), 212-219.

Santacroce, S. J. (2000). Support from health care providers and parental uncertainty during the diagnosis phase of perinatally acquired HIV infection. J Assoc Nurses AIDS Care, 11(2), 63-75.

Silberfarb, P. M. (1984). Psychiatric problems in breast cancer. Cancer, 53(3 Suppl), 820-4.

Silliman, R. A., Balducci, L., Goodwin, J. S., Holmes, F. F., & Leventhal, E. A. (1993). Breast cancer care in old age: what we know, don't know, and do. J Natl Cancer Inst, 85(3), 190-9.

Small, S. P., & Graydon, J. E. (1992). Perceived uncertainty, physical symptoms, and negative mood in hospitalized patients with chronic obstructive pulmonary disease. Heart Lung, 21(6), 568-74.

Small, S. P., & Graydon, J. E. (1993). Uncertainty in hospitalized patients with chronic obstructive pulmonary disease. Int J Nurs Stud, 30(3), 239-46.

Starr, P. (1982). The Social Transformation of American Medicine. United States: Basic Books, The Perseus Books Group.

Steptoe, A., Sutcliffe, I., Allen, B., & Coombes, C. (1991). Satisfaction with communication, medical knowledge, and coping style in patients with metastatic cancer. Soc Sci Med, 32(6), 627-32.

Stewart, D. E., Wong, F., Cheung, A. M., Dancey, J., Meana, M., Cameron, J. I., McAndrews, M. P., Bunston, T., Murphy, J., & Rosen, B. (2000). Information needs and decisional preferences among women with ovarian cancer. Gynecol Oncol, 77(3), 357-61.

Street, R. L. Jr. (1991). Physicians' communication and parents' evaluations of pediatric consultations. Medical Care, 29(11), 1146-1152.

Suominen, T. (1992). Breast cancer patients' opportunities to participate in their care. Cancer Nurs, 15(1), 68-72.

Tattersall, M. H., Butow, P. N., & Clayton, J. M. (2002). Insights from cancer patient communication research. Hematol Oncol Clin North Am, 16(3), 731-43.

Thomas, A. G., Jemal, A., & Thun, M. J. (2001). Atlanta, Georgia: American Cancer Society.

Thompson, T. L. (1998). The patient/health professional relationship. in L.D. Jackson & B.K. Duffy (Eds), Health Communication Research (pp. 37-55). Westport, CT: Greenwood Press.

Tomlinson, P. S., Kirschbaum, M. H. B., & Anderson, K. H. (1996). The influence of illness severity and family resources on maternal uncertainty during critical pediatric hospitalization. American Journal of Critical Care, 5(2), 140-6.

Turk-Charles, S., Meyerowitz, B. E., & Gatz, M. (1997). Age differences in information-seeking among cancer patients. Int J Aging Hum Dev, 45(2), 85-98.

U.S. Department of Education . (2002). Washington, DC: U.S. Government Printing Office.

Underwood, S. M. (1999). Breast cancer screening among African American women: addressing the needs of African American women with known and no known risk factors. J Natl Black Nurses Assoc, 10(1), 46-55.

Utley, R. (1999). The evolving meaning of cancer for long-term survivors of breast cancer. Oncol Nurs Forum, 26(9), 1519-23.

Verbrugge, L. M. (1985). Gender and Health: An update on hypotheses and evidence. Journal of Health and Social Behavior, 26, 156-182.

Verbrugge, L. M. (1990). Pathways of health and death. in R. D. Apple (Ed), Women: Health and medicine in America (pp. 41-59). Garland.

Vinokur, A. D., Threatt, B. A., Caplan, R. D., & Zimmerman, B. L. (1989). Physical and psychosocial functioning and adjustment to breast cancer. Long-term follow-up of a screening population. Cancer, 63(2), 394-405.

Waidmann, T. A., & Rajan, S. (2000). Race and ethnic disparities in health care access and utilization: an examination of state variation. Med Care Res Rev, 57 Suppl 1, 55-84.

Ware, J., Snyder, M., & Wright, W. (1976). Washington DC: Department of Health and Human Services.

Watson, M., Haviland, J. S., Greer, S., Davidson, J., & Bliss, J. M. (1999). Influence of psychological response on survival in breast cancer: a population-based cohort study. Lancet, 354(9187), 1331-6.

Webster, K. K., & Christman, N. J. (1988). Perceived uncertainty and coping: post myocardial infarction. Western Journal of Nursing Research, 10(4), 384-396.

White, R. E., & Frasure-Smith, N. (1995). Uncertainty and psychologic stress after coronary angioplasty and coronary bypass surgery. Heart Lung, 24(1), 19-27.

Wiener, C. L., & Dodd, M. J. (1993). Coping amid uncertainty: an illness trajectory perspective. Sch Inq Nurs Pract, 7(1), 17-31; discussion 33-5.

Williams, D. R. (2002). Racial/ethnic variations in women's health: the social embeddedness of health. Am J Public Health, 92(4), 588-97.

Wilmoth, M. C., & Sanders, L. D. (2001). Accept me for myself: African American women's issues after breast cancer. Oncol Nurs Forum, 28(5), 875-9.

Wilmoth, M. C. P. R. N. (2001). The Aftermath of Breast Cancer: An Altered Sexual Self. Cancer Nursing, 24 (4), 278-286.

Wilson, S. E., Andersen, M. R., & Meischke, H. (2000). Meeting the needs of rural breast cancer survivors: what still needs to be done? J Womens Health Gend Based Med, 9(6), 667-77.

Wineman, N. M. (1990). Adaptation to multiple sclerosis: the role of social support, functional disability, and perceived uncertainty. Nurs Res, 39(5), 294-9.

Wineman, N. M., Schwetz, K. M., Goodkin, D. E., & Rudick, R. A. (1996). Relationships among illness uncertainty, stress, coping, and emotional well-being at entry into a clinical drug trial. Appl Nurs Res, 9(2), 53-60.

Wissow, L. S., Roter, D., Bauman, L. J., Crain, E., Kercsmar, C., Weiss, K., Mitchell, H., & Mohr, B. (1998). Patient-provider communication during the emergency department care of children with asthma. The National Cooperative Inner-City Asthma Study, National Institute of Allergy and Infectious Diseases, NIH, Bethesda, MD. Med Care, 36(10), 1439-50.

Wong, C. A., & Bramwell, L. (1992). Uncertainty and anxiety after mastectomy for breast cancer. Cancer Nursing, 15(5), 363-71.

Wonghongkul, T., Moore, S. M., Musil, C., Schneider, S., & Deimling, G. (2000). The influence of uncertainty in illness, stress appraisal, and hope on coping in survivors of breast cancer. Cancer Nurs, 23(6), 422-9.

Woo, B., Dibble, S. L., Piper, B. F., Keating, S. B., & Weiss, M. C. (1998). Differences in fatigue by treatment methods in women with breast cancer. Oncol Nurs Forum, 25(5), 915-20.

Wyatt, G., & Friedman, L. L. (1996). Long-term female cancer survivors: quality of life issues and clinical implications. Cancer Nurs, 19(1), 1-7.

Wyatt, G. E., Desmond, K. A., Ganz, P. A., Rowland, J. H., Ashing-Giwa, K., & Meyerowitz, B. E. (1998). Sexual functioning and intimacy in African American and white breast cancer survivors: a descriptive study. Womens Health, 4(4), 385-405.

Wyatt, G. K., & Friedman, L. L. (1998). Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer. Oncol Nurs Forum, 25(4), 761-8.